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ABSTRACT

The report details accomplishments in the second year of a project serving 136 infants thought to be at high risk for developmental disabilities because of prematurity and serious illness. The project features a developmental intervention begun in the intensive care nursery (ICN) and continued in the infant's home during the first year of life. A summary of accomplishments for the year cites establishment of a parent support group and adoption of a new assessment instrument for premature infants. Each of nine project objectives is then addressed in terms of activities and accomplishments as well as slippages or modifications of objectives. The objectives include providing individualized programs of developmental care and therapy, educating and involving ICN nurses in developmental therapy, educating and involving parents, providing followup from ICN to secondary care nurseries, preparing a handbook about developmental therapy for parents, preparing a training manual for parent educators, and demonstrating the effectiveness of the ICN developmental therapy program in obtaining continued funding. Appended material includes samples of infant assessment and parent questionnaires. (CL)

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SECOND ANNUAL REPORT

Intensive Care Nursery (I.C.N.) INTERACT PROJECT

Child Development Center
Children's Hospital Medical Center
Oakland, California

Grant Number: G008000195
1981-1982

CFDA: 84.024A

Nancy Sweet, Project Director

EC 151087

DEPARTMENT OF HEALTH, EDUCATION & WELFARE
OFFICE OF EDUCATION
WASHINGTON, D.C. 20202

PROGRAM PERFORMANCE REPORT (Discretionary Grants)

FORM APPROVED
OMB NO. 51-R1091

Further monies or other benefits may be, but will not necessarily be, withheld under this program unless this report is completed and filed as required by existing law and regulations *(45 CFR 121, GSA FMC 74-7)*

Part I

All grantees with awards from programs listed under "General Instructions" above respond.

1. Date of Report:	2. Grant Number:
7/30/82	G008000195
3. Period of Report: From:	**To:**
July 1, 1981	June 30, 1982

4. Grantee Name and Descriptive Name of Project:
ICN Interact Project (originally approved as the High-Risk ICN Project)
Child Development Center, Children's Hospital Medical Center
Oakland, Ca. 94609

Certification: I certify that to the best of my knowledge and belief this report *(consisting of this and subsequent pages and attachments)* is correct and complete in all respects, except as may be specifically noted herein.

Typed Name of Project Director(s) or Principal Investigator(s):	Signature of Project Director(s) or Principal Investigator(s):
Nancy Sweet	Nancy Sweet

Part II *("Accomplishment" Reporting)*

A. All grantees, except for those with awards under 13.443 are to respond to this Section A. Grantees under 13.443 go to B of Part II.

All grantees with awards under 13.444 except those supported solely for "Outreach" activities are to follow the organization of categories listed below in presenting their performance reports. The categories are based on activities common to all Early Childhood projects with the exception noted above for projects solely supported for outreach activities.

(1) Direct and Supplementary Services for Children's Services
(2) Parent Family Participation
(3) Assessment of Child's Progress
(4) Inservice Training for Project Staff
(5) Training for Personnel from other Programs or Agencies
(6) Demonstration and Dissemination Activities
(7) Coordination with other Agencies
(8) Continuation and Replication

The grant application for programs 13.445, 13.446, 13.450, and 13.520 provided for the following functions or activities as categorical headings in the budget and narrative sections:

Research and Development	Dissemination
Demonstration/Service	Preservice/Inservice
Evaluation	Training

Programs 13.451, and 13.452 do not usually require a breakout since the primary function or activity is intrinsic to the respective program.

For each of the above programs, functions, or activities *(as well as those of special import for certain projects, e.g., replication, advisory councils, parent involvement)*, discuss the objectives and subobjectives presented in the approved application *(in narrative format)* in terms of:

(a) Accomplishments and milestones met.
(b) Slippages in attainment and reasons for the slippages.

Refer back to your application and utilize your quantitative quarterly projections, scheduled chronological order and target dates, and data collected and maintained as well as criteria and methodologies used to evaluate results for (a) and (b). For grantees under 13.444, in discussing training of personnel from other programs, include descriptions of types of training, institutions or organizations involved, and numbers of trainees and hours of training received.

Also highlight those phases of the plans of action presented in your application that proved most successful, as well as those that upon implementation did not appear fruitful. NOTE: Outreach grantees are to discuss accomplishments and slippages in terms of replication and stimulation of services, resources provided and field testing and dissemination and training in terms of types of personnel receiving training and the number of hours involved.

Grantees finishing this portion of Part II, go to C of Part II.

B. Reporting for Grantees under 13.443 *(Research and Demonstration)*.

Discuss major activities carried out, major departures from the original plan, problems encountered, significant preliminary findings, results, and a description and evaluation of any final product. Either include copies of, or discuss information materials released, reports in newspapers, maga-

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using the Assessment of Premature Infant Behavior (APIB)

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Description of Follow-Up Model

ICN Interact Conference Agenda:
The ICN: Intervention and Follow-Up

zines, journals, etc.; papers prepared for professional meetings; textual and graphic materials; completed curriculum materials and instructional guides, or drafts if in a developmental stage, special methods, techniques and models developed; scales and other measuring devices used.

When finished with this portion of Part II, 13.443 grantees go to C of Part II.

C. All grantees are to respond to this section C. Discuss the following:

(1) Unanticipated or anticipated spinoff developments *(i.e., those which were not part of your originally approved subobjectives, but which are contemplated within the purpose of the Education for the Handicapped legislation, such as new cooperative inter-agency efforts, a decision by volunteer(s) to pursue a career in special education, new public school policy to integrate handicapped children into regular classrooms, enactment of mandatory or other State legislation affecting early education, relevant new course offerings at universities, etc.).*

(2) Where outputs are quantified in response to any portion of Part II, relate quantifications to cost data for computation of unit costs. Analyze and explain high-cost units.

(3) Indicate other matters which you would like OE to know about *(e.g., community response to the project, matters concerning the project's working relationship with OE, technical assistance of OE staff, or any other relevant subject.).*

Part III

All grantees with a Demonstration/Service function or activity, except for 13.444 grantees who are solely supported for "outreach" activities, are to complete Tables IA, IB, and IC. All grantees under 13.451, as well as those under other handicapped programs with a Preservice/Inservice Training activity are to complete Table II. All grantees under 13.444 except those who are supported solely for "outreach" activities, are to complete Tables IIIA and IIIB.

Table IA – Demonstration/Service Activities Date

Children

Enter actual performance data for this report period into the appropriate boxes. Use age as of the time of the original application, or the continuation application, whichever is later. On lines above line 11, count multihandicapped individuals only once, by primary handicapping condition, and indicate the number of multihandicapped in line 12. Data for lines 1 through 11 are for those directly served, i.e., services to those enrolled or receiving major services, and not those merely screened, referred or given minimal or occasional services.

Type of Handicap	Number of Handicapped Served by Age					
	Ages 0-2	Ages 3-5	Ages 6-9	Ages 10-12	Ages 13-18	Age 19 and Over
1. Trainable Mentally Retarded						
2. Educable Mentally Retarded						
3. Specific Learning Disabilities						
4. Deaf-Blind						
5. Deaf/Hard of Hearing						
6. Visually Handicapped						
7. Seriously Emotionally Disturbed						
8. Speech Impaired						
9. Other Health Impaired	36					
10. Orthopedically Impaired						
11. Total	36					
12. Multihandicapped						

If the data in the above table differ by more than 10 percent from the data originally presented in your approved application, please explain the difference.

Table IB

Project Staff Providing Services to Recipients in Table IA

Type of Staff	Number	
	Full-time	Part-time (As Full-time Equivalents)
Professional Personnel (excluding teachers)		1.5
Teachers		1
Paraprofessional		

Table IC

If applicable: Services to Those Handicapped Not Included in Table IA

Service	Number of Handicapped
Screened	27
Diagnostic and Evaluative	
Found to Need Special Help	
Other Resource Assistance	

Table II

Preservice/Inservice Training Data

Handicapped Area of Primary Concentration	Number of Persons Received Inservice Training	Number of Students Received Preservice Training by Degree Sought			
		AA	BA	MA	Post-MA
Multihandicapped					
Administration					
Early Childhood					
Trainable Mentally Retarded					
Educable Mentally Retarded					
Specific Learning Disabilities					
Deaf/Hard of Hearing					
Visually Handicapped					
Seriously Emotionally Disturbed					
Speech Impaired					
Orthopedically and Other Health Impaired					
TOTAL					

If data in Table II above differ by more than 10 percent from those in your approved application, explain.

Table IIIA
Placement of Children Participating in Early Childhood Program During Reporting Period

Indicate the placement of children who left your project during the year covered by this report period.
NOTE: Count each child only once by primary type of placement below.

TYPE OF PLACEMENT			NUMBER OF CHILDREN	
			FULL-TIME	PART-TIME
INTEGRATED PLACEMENT *(i.e., in regular programs with children who are NOT handicapped)*	Nursery schools			
	Day-care programs			
	Head Start			
	Pre-kindergarten			
	Kindergarten			
	Primary grades	First		
		Second		
		Other		
SPECIAL EDUCATION PLACEMENT *(i.e., in classes only for handicapped children but situated in regular private or public school)*	Pre-kindergarten			
	Kindergarten			
	Primary grades	First		
		Second		
		Other		
INSTITUTIONAL PLACEMENT	Scheduled to remain in Early Childhood Program in coming year			
	Other *(specify)*			

Table IIIB

	NUMBER		PERCENT
Cumulative number of children entered into integrated placement *(if known)* prior to this report period →		Estimated retention rate of cumulative number in integrated placement →	

N.A. Children are one year of age when they leave the ICN Interact Project

INTENSIVE CARE NURSERY INTERACT PROJECT

ADDRESS: Child Development Center
Children's Hospital Medical Center
51st & Grove Streets
Oakland, CA 94609

TELEPHONE: (415) 428-3351

FUNDING: Office of Special Education
U.S. Department of Education:

Three-year Model Program Grant
Early Handicapped Childrens Education Program

PROJECT STAFF: Nancy Sweet, Administrative Director; Richard Umansky, M.D., Medical Director; Kathy VandenBerg and Bette Flushman, Infant Educators; Diane Valentin, ICN Follow-Up Nurse.

CHARACTERISTICS OF TARGET POPULATION: A total of 136 medically high risk infants, prone to developmental disabilities by reason of prematurity and serious neonatal illness. These infants are identified in the Intensive Care Nursery of Children's Hospital Medical Center, a teritiary treatment resource for N.I.C.U.'s in the Northern California area.

PROGRAM FOR CHILDREN: Developmental intervention which begins in the Intensive Care Nursery at Children's Hospital, continues when recovering infants are returned to local secondary care I.C.N.'s and extends into the infant's home upon release. Developmental intervention is based on neonatal assessment and multidisciplinary review. Individual Developmental Intervention Plans include daily developmental therapy goals, environmental modifications, and procedures for participation of parents and I.C.N. nurses. Neonatal assessment, home-based follow-up, and developmental therapy if needed will be provided during the first year of life.

PROGRAM FOR PARENTS: Education and support which will facilitate attachment, care and developmentally appropriate interaction with the high risk infant beginning in the intensive care nursery and later at home.

SPECIAL FEATURES OF PROGRAM: 1) Model which combines developmental intervention in the Intensive Care Nursery with comprehensive neonatal follow-up during the first year of life. 2) Training and participation of ICN Nurses at Children's Hospital ICN and selected secondary care ICN's in developmental intervention with high risk infants.

CRITERIA FOR REFERRAL: 1) Projected recovery after hospitalization of at least one month in Children's Hospital ICN or Children's and secondary care hospitals. 2) Parent or primary caregiver who can work with project staff.

ICN INTERACT PROJECT

SECOND YEAR PROGRESS REPORT, JULY 1, 1981 - JUNE 30, 1982

I. SUMMARY OF ACCOMPLISHMENTS

1. During the second project year 36 high risk infants hospitalized one month or more in the ICN were served as proposed. The second year babies were admitted at an even younger gestational age than first year babies. Average length of ICN stay and project intervention in the ICN was longer, an average of 15.2 weeks, and a range of 5 to 65 weeks. By the end of the second year a total of 72 project and 41 non project babies received developmental services in the ICN.

2. A new assessment of premature infants was adopted for use in the ICN. The Assessment of Premature Infant Behavior (APIB) permits more detailed project evaluation and developmental monitoring.

3. The project participated in the initiation of a support group for parents of premature infants and in efforts to improve the ICN environment for infants, parents, and staff.

4. Developmental follow-up was provided as proposed for babies leaving the ICN. A total of 113 home visits and 106 follow-up clinic visits, which included 22 formal developmental assessments with the Bayley Scales of Infant Development, were provided during the second year. The majority of those tested were performing in the normal range on the Bayley Scales at one year corrected age. Five infants were referred to early intervention programs for handicapped infants and five others were scheduled for continued developmental monitoring.

5. A handbook for parents in the ICN was drafted. "Developmental Steps, a Guide For Parents To Infant Development In the ICN" was revised and sent for editing by the technical assistance agency WESTAR. The handbook will be again revised then distributed for use in the third year.

6. Final plans for data collection and analysis pertinent to evaluation of the project were made. Evaluation will be made of infant development, parent participation, nurse participation and impact on the ICN environment.

7. Significant efforts were made to share project expertise and procedures with others. This included presentations at several conferences, preparation of three papers for publication, and radio and magazine coverage.

8. The project director participated on a number of state and federal advisory committees concerned with improvements in services to infant with special needs. Several legislative and policy initiatives resulted.

9. The project participated in the establishment of ongoing developmental follow-up services by a Neonatal Follow-Up Clinic for high risk infants leaving the ICN.

I.C.N. INTERACT PROJECT

SECOND YEAR PROGRESS REPORT, JULY 1, 1981 - JUNE 30, 1982

II. REVIEW OF PROJECT OBJECTIVES

Accomplishments are best reviewed in the context of project objectives as originally proposed, with modifications reported in the interim progress report (July 1 - Dec. 31, 1981). The primary goal of the ICN Interact Project is to foster the developmental processes of premature and seriously ill newborns who are at great risk for handicapping conditions. Nine subordinate objectives identify major project activities.

The format requested for accomplishment reporting by OE form 9037-I is categorical rather than by project objectives. In order to comply with the requested format, the following list identifies which objectives correspond to each category:

Program Performance Report Category	Project Objectives
1. Direct and Supplementary Services for Children's Services	Objective 1,4,5
2. Parent/Family Participation	Objective 3
3. Assessment of Children's Progress	Objective 1,5,8
4. Inservices Training for Project Staff	Objective 2
5. Training for Personnel from Other Programs or Agencies	Objective 4
6. Demonstration and Dissemination Activities	Objective 6,7,8
7. Coordination with Other Agencies	Objective 4,5
8. Continuation and Replication	Objective 8,9

In narrative form, 1. Direct and Supplementary Services for Children's Services in the ICN Interact Project include the intervention program in the ICN (objective 1), follow-up in secondary care nurseries (Objective 4) and at home (Objective 5). 2. Parent/Family Participation in the INC Interact Project consists of involvement in both the ICN intervention (Objective 3) and home follow-up program (Objective 5). 3. Assessment of Child's Progress occurs during the ICN intervention program (Objective 1) and follow-up at home (Objective 5), and is a major component of the project's overall evaluation plan (Objective 8). 4. Inservice Training for Project Staff focuses on training for ICN nurses (Objective 2), since existing project staff are all highly trained. 5. Training for Personnel from Other Programs or Agencies is provided to personnel from secondary care hospitals (Objective 4). 6. Demonstration and Dissemination activities include preparation of two products: a handbook for parents (Objective 6) and a training manual for health care staff (Objective 7), as well as activities related to demonstration of the effectiveness of the program (Objective 8).

7. Coordination with Other Agencies, in the ICN Interact Project, is comprised of coordination follow-up in secondary care hospitals (Objective 4) and at home (Objective 5). 8. Continuation and Replication are represented by Objective 9 and 8 respectively.

Objective 1: To provide individualized programs of developmental care and therapy to 36 ICN patients during the second project year.

A. Activites and Accomplishments

This objective has been accomplished. During the second project year, as during the first project year, 36 infants who required intesive care for one month or more were identified and admitted to the project. An additional 27 infants were screened and assessed by the project.

1. Description of Infant Population Referred by Project

As proposed, developmental intervention in the ICN was initiated with 36 infants admitted to the project between July 1, 1981 and June 30, 1982. Thirty four of the 36 infants admitted were premature infants of less the 37 weeks gestational age.

A significant trend toward earlier referrals to the project of very premature babies occurred from the first to the second year. We attribute this to a combination of the project's success in the nursery with a concurrent improvement in the survival rate for the very premature infant. In the second year 30 infants were admitted who were 31 weeks gestational age or less, while in the first year only 21 of the 36 infants were that age. In the second year 9 infants were that age. In the second year 9 infants were less than 28 weeks gestational age, while in the first year 6 were that premature. The age of the infant population has profound implications for the type of developmental intervention which is possible and appropriate. It is important to note that, thanks to the cooperation of the neonatology, nursing and other ICN staff, the ICN Interact Project is unique in its opportunity to work with very premature infants and families from near the beginning of life in the ICN.

The number of full-term babies who met the project's length-of-stay criterion fell from 4 in the first year to 2 in the second. Of the premature babies, all had a diagnosis of RDS (respiratory distress syndrome), with 12 subsequently developing significant BPD (bronchopulmonary dysplasia). Five of the 8 of these BPD babies who had been discharged by the end of the project went home on oxygen. Nine of the infants have mild RLF (retrolental fibroplasia, or retinal damage).

Geographical and ethnic distribution of the 36 famlies admitted in the second project year is as follows: Fifteen infants are from Contra Costa County, and 21 infants are from Alameda County, of whom 15 are from urban Oakland. The population is 55% black, 36% caucasian, 6% hispanic and 3% asian.

In addition to the 36 infants admitted to the project another 27 infants were screened or assessed by the project, with subsequent developmental recommendations to neonatologists, nurses and parents. By the end of the second project year therefore, a total of 72 project and 41 non-project newborns had received developmental services in the ICN.

Non-project infants fall into three categories: 1) infants who are not expected to meet the length-of-stay admission criterion, b) infants who may meet the length-of-stay criterion but come from outside the project's service area, and c) infants diagnosed as handicapped and in need of more intensive follow-up services than the project provides.

Infants who have been diagnosed as handicapped are referred to a specially trained occupational therapist who is part of the developmental therapy team. After assessment of the infant by the infant educators, and with their assistance, the occupational therapist then provides a developmental therapy program for the handicapped newborn. These infants are referred for continuing developmental services by the hospital's own Parent-Infant Project (a previous HCEEP model program) or some other infant program in the area. Those infants referred to the Parent-Infant Project continue to be seen by the same occupational therapist, thus ensuring continuity of developmental services from the ICN to home. The handicapped infants are also referred to the Child Development Center's diagnostic services for ongoing developmental follow-up during the preschool years.

The length of ICN stay for project infants (which corresponds to the length of participation in the ICN phase of project services) ranged from 5 to 65 weeks, with an average of 15.2 weeks. This represented an increase in both range and average from the first year when infants remained 2 weeks to 35 weeks, with an average of 11 weeks. It seems likely that these increases can be attributed to the survival of very premature infants as discussed earlier. If on the average these babies are spending almost their first 4 months of life in the ICN environment, it is clear that a developmental concern and perspective is most appropriate.

By the end of the project year 26 of the 36 second year admissions had progressed to the home follow-up program. Nine of the 36 infants received interim care at community care hospitals as compared to 12 the previous year. This is consistent with the trend noted in previous reports toward fewer transfers from our tertiary ICN to secondary hospitals. Babies are relased earlier and more frequently directly to their homes.

2. Assessment of Individual Developmental Needs

During the second project year significant progress was made in developing and implementing appropriate techniques for assessing the developmental needs of the premature and critically ill newborn in the Intensive Care Nursery setting. As was discussed in the first annual report this process has required several steps. By the end of the first year 1) a modification of the Brazleton Newborn Assessment Scale (BNAS) suitable for the recuperating premature infant was developed and implemented.

Based on first year technical assistance by Dr. Peter Gorski of Mt. Zion Hospital, obtained through WESTAR, 2) a supplemental Developmental Observation was compiled and implemented. The Developmental Observation provides an assessment of the newborns individual responses to routine nursing care and social interaction, as reflected by changes in state, activity level and physiological indicators, including respiration and heart rate, color and so forth.

These assessments completed by project staff were supplemented by 3) an assessment completed by one or more of each infant's primary nurses. The Nursing Assessment of High-Risk Infant Behavior is a research tool development by Dr. Peter Gorski which records the nurse's perception of developmental characteristics of the baby.

Assessment of individual developmental needs also required 4) Assessment of the ICN Environment. The types of physical and social stimulation, medical and caregiving procedures vary from baby to baby and over time as the baby convalesces.

By the end of the first project year all four assessments were in use. Copies of each of the assessment forms were included in the first annual report.

These assessments represented significant and exciting steps forward in identifying the characteristics of premature infant behavior. As such they were of value in developing intervention programs, and in educating ICN nurses and parents about individual infant needs. For the purposes of evaluating the intervention program, however, they had three major drawbacks: 1) developed as clinical tools, they lacked the reliability and validity of standardized assessment procedures available for older children; 2) their non-quantified and non-sequential structures made changes overtime difficult to analyze or interpret; and 3) correlation with assessments of behavior and development after term (such as the Bayley Scales of Infant Development) was unknown.

Late in the first year project staff learned of an assessment of premature infant behavior based on the BNAS under development by Als, Lester, Tronick and Brazleton. Since this assessment promised to eliminate some of the drawbacks just identified, project staff sought technical assistance by Dr. Heideliese Als through WESTAR during the second project year.

Dr. Als provided pre-publication copies of the Assessment of Premature Infant Behavior (APIB) which the infant educators began using. As part of WESTAR's technical assistance Dr. Als made a three day site visit to the project in March. Project staff were observed and certified in use of the APIB. Clinical and evaluation applications of the assessment were discussed extensively with project staff and also with ICN and hospital staff in special meetings and grand rounds.

Project staff believe that the APIB is useful as a behavioral/developmental assessment tool for trained ICN developmental specialists for several reasons. It has a reliability/validity base established through research. It is quantified in such a way that a longitudinal comparison of assessments is feasible. Observations may begin with a significantly premature baby, even before non-essential physical handling is appropriate. Finally, research is underway by Dr. Als and others correlating APIB performance with later performance on the Bayley Scales and other infant development assessments.

Perhaps most important to project staff, the theoretical base of the APIB is compatible with the intervention model and clinical applications needed by the ICN Interact Project. The APIB can provide detailed developmental information of value even to highly skilled intervention staff, and with proper interpretation, to medical staff and parents in the ICN.

On the basis of six months of use of the APIB project staff have determined that it is the best assessment tool for staff use (though the Developmental Observation and BNAS modification are felt to be more useful for beginning developmental specialists in the ICN). Since the APIB essentially incorporates many of the items or purposes of the earlier project-developed assessments, and since the APIB demands several hours to administer, score and interpret, the project has replaced use of the earlier infant assessments with use of the APIB alone. Nurses assessments and occasional ICN environment assessments are still completed.

Project staff have developed a narrative summary of the APIB and, with the help of Dr. Als, a format for incorporating impressions based on the APIB into the infants medical records and discharge summary. A sample of the APIB scoring, narrative summary, medical records summary and discharge evaluation are included in the Appendix.

The ICN Interact Project is a national leader in developing intervention techniques appropriate to the hospitalized premature infant population. A decision was made to realize the innovative potential of the project. Comprehensive assessment and intervention techniques have been developed or adopted, even though the several changes in data collecion will make rigorous program evaluation more difficult.

3. Individualized Developmental Programs

A plan of developmental intervention is prepared for each project infant by the infant educators. The developmental plan is based on the assessments just described, as well as the Assessment of Parent-Infant Interactions and the medical status and care of the infant. The plan identifies long term goals differentiated for preterm and postterm infants which are based on project preterm and postterm curricula. The plan is the basis for weekly developmental goals and activities which are posted at the infant's bedside. The preparation, implementation and evaluation of these developmental programs is unchanged from the description included in the first annual report. A recent addition has been the weekly developmental update which summarizes changes in activities and infant development for review by the project pediatrician monitoring project babies.

B. Slippages or Modifications of Objective 1

On the basis of grant budget constraints, the original proposal of serving 50 ICN infants with the addition of a half-time educator in the second year was modified to serving a target population of 36 infants with existing staff. All activities under this approved modification of Objective 1 were accomplished as proposed.

Objective 2: To education and enlist the ICN nurses in providing developmental therapy as well as in the task of modifying the ICN environment for the infant's benefit.

A. Activities and Accomplishments

Second year activities related to effective involvement with ICN nurses were accomplished as proposed. An important element of developmental services to infants in the ICN is the cooperative working relationship between ICN nurses and project staff.

First year accomplishments exceeded original objectives. Activities fell into four general categories:

1. education for nurses
2. a support group for nurses
3. nurse participation in assessment, program planning, intervention and follow-up
4. project participation in joint and nursing initiated activities to improve the ICN environment.

During the second year these types of activities continued with particular emphasis on new methods of involvement of the individual ICN nurse in assessment, program planning, intervention and follow-up of project infants.

1. Education for Nurses

A number of ICN nurse education activities were conducted successfully during the first year. These included a training series for nurses in developmental intervention, six presentations to local conferences attended by ICN nurses and an open house/orientation for hospital staff. The project also presented a well-attended and highly evaluated one day conference: "The Intensive Care Nursery, Intervention and Follow-Up". This conference, conducted in June, emphasized the significance of the ICN nurse in developmental intervention. A copy of the agenda is included in the Appendix.

According to second year timelines, between July 1 and September 1 the project was to assess the need for, and provide as needed, an additional training series for new ICN nurses. The conclusion was that the recent (June) conference on developmental intervention in the ICN met the needs of new nurses, and an additional training series was not warranted. Instead, the project has prepared a videotape of an earlier training series. This can be made available for new nurses on an individual and flexible basis. The project has also begun work toward a third year product for training health personnel which is described under Objective 7.

A significant opportunity for nurse education was provided in February during a site visit for technical assistance purposes by Dr. Heideliese Als, Harvard Medical School ICN nurses from Children's and related secondary care personnel, as well as other hospital personnel, were invited to a special grand rounds presentation by Dr. Als on the behavioral assessment of preterm infants. This presentation was followed later in the day by an extended luncheon presentation and discussion with Dr. Als to which a smaller number

of key nursing and other medical staff were invited. These presentations were well received, and reinforced the developmental focus of the ICN Interact Project.

The most effective educational approach with nurses in the ICN is the individualized approach, employing daily situations in the ICN to illustrate and encourage a developmental perspective. This is particularly true for the large and fluctuating nursing staff of a big tertiary ICN such as ours, which must rely upon both highly experienced and developmentally sophisticated primary care nurses as well as new and on-call nurses. As the project refined its model of nurse participation in infant assessment, program planning, intervention and follow-up during the second year, opportunities for individualized ICN nurse education expanded.

Although group training sessions for our ICN nurses were determined to be not necessary and less effective than individualized training, such group training continued to be offered to nurses from secondary care hospitals to which project babies are transferred. Five 1-2 hour training sessions in developmental principles were offered to five groups of ICN nurses as an integrated part of Children's ICN Outreach Training Program.

2. Support Group for Nurses

Although not originally proposed, the project has found it valuable to provide an opportunity for primary care nurses to discuss their feelings about their work and the infants they care for. This effort has grown out of an informal presentation on attachments by the project psychologist, who is an expert in the area. She met a number of times with the nurses on a monthly basis.

Primary care nurses experience stresses above and beyond the demanding care of sick and fragile infants. Attachment is likely to the infant for whom they provide intensive and life sustaining care for weeks or months. This can pose problems in their relationship with the infant's parents, particularly mother. Loss is inevitable and abrupt when the infant leaves or dies. Nurses often need a recovery period once one primary care nursing assignment ends before they regain the emotional stamina to take on another.

Discussion and peer support are helpful in dealing with some of these stresses which can dramatically affect the nurse-infant interaction. The support group offered by the project is low-key and voluntary, continuing only as the nurses have requested it.

Support group meetings began in response to particular difficult attachment/separation problems for ICN nurses presented by several infants requiring long-term hospitalizations. These meetings began in the spring and continued on a month-by-month basis into the fall of 1981. The meetings ceased once those problems were resolved, but nurses were told that they can be reinstituted if needed.

3. Nurse Participation in Infant Assessment, Program Planning, Intervention and Follow-Up

During the second year these were the key daily activities related to Objective 2. The ICN Interact Project's intervention philosophy emphasizes involvement of all primary caregivers, nurses and parents,

and concern with the developmental aspects of the infant's total 24 hour a day environment. The nurses who care for each baby are a significant element in the infant's early experiences. Though medical caregiving is their primary responsibility, there are many ways in which they can effect developmental intervention objectives as well. The project has two types of goals in involvement of nurses. It encourages nurses to carry out developmental activities prescribed in the infant's weekly program. Perhaps even more importantly, it encourages nurses to provide care in ways that will be developmentally optimal for the individual infant. Our experience has been that there is tremendous individual variation in nurse participation in both areas; but that with information and involvement many ICN nurses can be sensitive, effective developmental interventionists.

Assessment. Nurses are involved as much as possible in the assessment of the behavior and development of project infants in the ICN. Sharing such observations with the infant educators and other project staff has been identified as of great educational and supportive value by many of the ICN nurses.

Nurses participate in formal assessment in two ways. First, the nurse frequently assists the infant educator in direct developmental assessment of the infant. Prior to the project's adoption in February of the new Assessment of Premature Infant Behavior (APIB) developed by Dr. Heideliese Als, et.al, nurses assisted in the completion of every Developmental Observation assessment.

The Developmental Observation procedures were developed by project staff and are described in the First Year Report. During the Developmental Observation the nurse carried out requested routine handling procedures while the infant educator recorded the infant's behavioral and physiological responses. These observations then provided the basis for handling and developmental intervention recommendations to the nurse. Since the nurse received immediate feedback from this observation about the effects of her handling of the baby, the assessment procedure itself was frequently a useful nurse education tool.

The Assessment of Premature Infant Behavior (APIB) was adopted for use after project staff were certified in administering the assessment by Dr. Als. Administration requires direct handling of the baby, much like the Brazleton Newborn Assessment Scale on which it is based. Therefore, current assessment techniques do not permit as much direct nurse participation as needed earlier. However, project staff attempt to involve the nurses in observation and commenting on the assessment procedures when feasible. Since the APIB generates detailed behavioral information about the babies in their care, many nurses are interested in the assessment procedures and scoring.

Nurses, particularly primary care nurses, also are asked to complete an assessment, the Nursing Assessment of High Risk Infant Behavior, which was developed for research by Dr. Peter Gorski of Mr. Zion Hospital in San Francisco. A copy of this assessment was included in the First Annual Report.

This provides the infant educators with information regarding the consistency of infant behavior seen more briefly during their assessments. It also reveals how the nurse perceives the individual infant, identifying problem areas (such as irritability) which may be appropriate for developmental intervention, or areas of individual nurse education (such as normal and atypical muscle tone characteristics of the premature infants) which may be valuable.

Program Planning. The infant educators attempt to involve nurses in the program planning for an infant, particularly when the infant has primary care nurses who know her or him well. Individual nurses are consulted on a daily basis for their observations and suggestions. Primary care nurses are invited to a weekly multidisciplinary program planning meeting, at which plans and progress are reviewed.

Intervention. As mentioned earlier, nurses are regarded as vital to effective developmental intervention. Nurses are asked to carry out the developmental activities listed on the infant's weekly goal sheet. Many of them do, and record and describe their efforts. In accordance with the project's philosophy of intervention, many of the prescrived activities are compatible with or directly related to routine care procedures. As an example, the infant educator may suggest that an infant be positioned frequently by the nurse on his stomach rather than his back because he seems better able to soothe and organize himself in that position. Or the infant educator may determine that a baby is easily overstimulated, with a resulting recommendation that the nurse either elicit the baby's visual attention or talk to the baby during routine caregiving procedures, but not both at once.

The infant educator frequently asks the nurse to assist her with daily observations of the characteristic behavior and responses of the infant. The infant educator will instruct the nurse as to what to look for. The infant educator thus gets information about the consistency of the infant's behavior, while the nurse is given a developmental focus and observation skills which may be helpful in caregiving. For example, one week the infant educator may ask the nurse to note when and for how long the baby achieves an alert state, identifying for the nurse distinguishing features of different states in the premature infant. The infant educator gains information which is helpful in timing her own interventions. The nurse becomes aware of state differences and the pattern for that individual baby. When the weekly developmental activity then becomes gaining the baby's visual attention during alert states,the nurse will be able to carry out the activity more effectively. The nurse has gained information and an observational skill which may be used with other infants in the nurse's care.

As the premature infant matures, and for term and post-term infants in the ICN, the educational program becomes msuch more active. The nurse is asked to change frequently the infant's crib environment of visual/auditory/prehension objects. The infant educator may show the nurse how to carry out an appropriate developmental activity and ask that she do it several times during the course of her shift each day. The nurse will be asked not only to carry out the activity but to evaluate its effectiveness with that infant.

Follow-Up. Once a baby leaves the ICN, the nurses generally hear nothing further. They get no feedback about the baby's course of development, or whether their interactions with the parent have been helpful. ICN staff get surprisingly little information which might help them modify non-medical procedures. A presentation at our June 1st conference by a panel of parents about their perceptions and feelings during their ICN experience had tremendous impact on ICN staff.

The ICN Interact Project has attempted to provide some feedback to ICN nurses through the conference and more routine procedures. One of the most effective has been the posting in the nurses lounge of follow-up reports on project infants once they leave the ICN. After a home visit the project's follow-up nurse will post a photograph and a brief report on the infant's health and development. This effort has been appreciated greatly by the ICN nurses.

Informal feedback also is provided to individual primary care nurses who are interested in what becomes of a baby in their care. The follow-up nurse and infant educators will make a point of informing these nurses about how the baby does when tranferred to a secondary care hospital or in the transition to home. Joint home visits with the follow-up nurse are also possible.

By the end of the second year questionnaires were requested from 23 parents who had completed project participation. This questionnaire provides evaluation not only of project participation, but of the parent's experiences in the ICN as well. Results of the questionnaire permit formal feedback to nurses and other ICN staff. A copy of the revised Parent Questionnaire is included in the Appendix.

4. Project Participation in Joint and Nursing Initiated Activities

Beginning in the first year and continuing during the second, project staff working with ICN nursing staff on several activities of major import for the quality of the ICN environment for infants, parents and staff. Some of these include: Parent Support Group. A support group for parents of premature infants was initiated in the first year by project staff, ICN nursing, social services and parents of ICN graduates. During the second project year the parent support group was made operational after a series of planning meetings. It now provides assistance to parents both during and after ICN hospitalization. Specific activites related to the Parent Support Group are described under Objective 3.

Organization of a Parent Room. Our ICN until recently has had no place for parents to spend time alone with their recovering babies. In spite of space limitations, the need for this has been recognized both by nursing and by the project. A small room leading directly off the ICN has been set up for parents for breastfeeding, developmental activities or quiet time with the baby. It has been equipped with materials useful to parents, such as pamphlets on the premature infant and on breast feeding the premature infant.

Changes in Nursing Care. Nursing is making continuing efforts to improve the quality of care for ICN infants. In addition to medical care procedures, nursing is actively incorporating developmental intervention techniques from the project and other sources.

An excellent example of this is provided in the draft of "Tiny Baby Care Guidelines" for nurses which was included in the interim report. Many of the infant educators' recommendations for reducing overstimulation of the very premature infant and for optimal handling can be found incorporated with nursing care recommendations.

Nursing is alert also to concerns with the parent-child relationship and the nurse's role in the development of attachment. The ICN nurses receive periodic reviews of the literature on attachment as part of their inservice training. Generally, ICN nurses encourage and assist, but do not pressure parents into handling their baby until they are ready to do so. Efforts to move toward primary care nursing are of great benefit to the parent and to the developing parent-child relationship, since the parent then has a consistent nurse to relate to, who gets to know parent and baby well.

Changes in Visiting Policies. Nursing is attempting to make parents feel more welcome in the ICN and has liberalized visiting policies. Parents are encouraged to spend time in the ICN whenever they can, and other relatives, including siblings and friends, are permitted to visit the ICN.

Design of a New ICN. A major building campaign by Children's Hospital will result in space for a new ICN next year. Nursing and project staff have been concerned with the design of a new ICN which provides both optimal medical and developmental environment for these infants. Developmental concerns include the physical organization of space and beds, noise and lighting levels, and space for parents.

Move Toward Primary Care Nursing. Nursing is attempting, and the project supports, a move toward nursing assignments for ICN infants by a consistent primary care nurse. There are tremendous benefits to infant and family of primary care. There are benefits and costs, however, to the individual primary care nurses and to ICN nursing as a whole. Some of costs are emotional; these costs and some project efforts to lessen them were reviewed under Nurse Support Group. Nursing has made several productive efforts to maximize the benefits and reduce the costs of primary care nursing. Though primary care nursing has not been accomplished completely, most project infants (who are the most premature and longterm ICN inhabitants, needing primary care the most) have had good primary care nursing.

B. Slippages or Modification of Objective 2

No slippages or significant modifications of this objective occurred in the second project year. The project met or exceeded timelines and proposed activities. Many unanticipated activities and benefits related to this Objective have occurred.

Objective 3: To educate and encourage the infant's parents to take part in the nurturing and care of the infant to enchance its recovery and development.

A. Activities and Accomplishments

Activities related to this objective have been accomplished as proposed. The sequence of contact, planning and interaction with the parent in the ICN which was detailed in the original proposal has been followed with each of the 36 project participants in the second project year.

The project attempts to assist the establishment of a basic attachment relationship between high risk newborns and their parents. Project staff provide information about current and anticipated capacities of these infants. They model handling and stimulation techniques. They help the parent identify cues and responses of the individual infant. They assist with feeding and soothing. Project staff are able to identify a meaningful role for the parent even in the ICN setting, which helps to establish the parent's primary role when the high risk infant goes home. They help prepare the parent for the often difficult task of caring for the high risk infant at home. They are able to talk with these parents about their feelings related to the high risk infant.

Three major components of parent involvement for further development in the second year were identified in the first year report. These include:

1) appropriate models and effective techniques for involving parents in the tertiary ICN setting. This is a unique setting for early intervention efforts. The highly technical medical setting, concerns about survival, patterns of caregiving and emotional responses to the premature or seriously ill infant all have a profound impact on the new parent in the ICN. The infant educator can be a key person in involving parents in the ICN setting. Infant development is one of the areas of care of the newborn in the ICN in which the parent can take an active role. The intervention model and techniques of parent involvement must be appropriate to this unique setting.

There have been three key accomplishments in this area during the second project year:

a. the role of the developmental specialist with ICN parents has been clarified and documented.

b. a parent support group has been initiated.

c. expertise in this area is being used in designing a guide for parents for use during and after ICN experiences. A draft of the manual "Developmental Steps" has been completed as proposed and described under Objective 6.

a. The role of the developmental specialist with parents: The model of the ICN Interact Project places strong emphasis on involving and working with parents to the extent feasible in the ICN setting. A

unique set of concerns and stresses are common for parents of high risk newborns in the ICN. Effective intervention cannot occur without recognition and incorporation of these concerns.

Educational and supportive components of project intervention with ICN parents will not be described here. They have been summarized in two articles by project staff in the forthcoming WESTAR publication, "Issues in Neonatal Care".

b.Parent Support Group: Through joint efforts by project staff, ICN nursing, social services and parents of ICN graduates, a support group for ICN parents was established during the second project year. Initial planning included consultation with two Bay Area support groups for parents of prematures, as well as review of materials from other programs which could be identified. Through a series of meetings a model of a parent-developed program (rather than staff-developed) emerged as most appropriate to our setting.

After preliminary meetings a survey was developed and mailed to more than 700 families who had had babies in the ICN in the recent past exploring interest in a parent support group. A total of 106 returned the survey. Summary data are included here.

Based on the response to the questionnaire a decision was made to go ahead with parent support group efforts. A number of activites ensued during the remainder of the project year:

1) an ICN Parent Support Group Advisory Committee was formalized. Meetings were schuled every few months.

2) a "coffee room" for ICN parents, staffed by graduate parents was established. This item was the most highly requested in the parent survey. Parents now are staffing the coffee room two evenings each week to allow informal support and discussion with current ICN parents.

3) a successful "graduate picnic" was planned and held, as was an ICN reunion which approximately 150 people attended.

4) several presentations were planned on the basis of survey responses. The first, "Coping When You Have a Premature or Sick Baby" was well attended and received.

5) a bulletin board for parents was established in the nursery.

6) the idea of a parent-to-parent support system or "hotline" was explored.

7) a search for funding for ICN Parent Support Group activities was initiated.

700+ mailed
106 surveys returned
1 letter

CHILDREN'S HOSPITAL MEDICAL CENTER

PARENT SUPPORT GROUP

1. As a parent with a sick newborn, what types of support would have been helpful to you?

	Helpful	Maybe	Not Helpful
a. Telephone contact with another parent	42	44	17
b. Visit with another parent	60	34	7
c. Parent "coffee room" at the hospital staffed by "graduate" parent willing to talk	82	18	6
d. Group meetings with graduate parents and other parents in the nursery	48	42	13
e. Programs on related topics	60	37	3

2. If you are interested in presentations, what topics would be of interest to you?

_____

_____

_____

_____

Suggestions (indicate if any of the following are of interest):

(2) 70 Coping with the birth of a sick or premature baby
(5) 49 Common medical problems in newborns (hyaline membrane disease, patent ductus, etc.)
(6) 47 Homecoming and the family
(3) 61 Longterm development of the sick or premature baby
(4) 43 Care and feeding of the premature baby
(7) 37 Community resources
(1) 51 Having another baby

3. Additional comments/suggestions: (Use other side if necessary)

Please complete the following to update our records:

Parent name(s) _____

Address _____

City, State, Zip _____

Child's name _____

PLEASE RETURN BY AUGUST 15. THANK YOU!!

Child's birthdate _____

Miscellaneous Suggestions for Presentations

*Breast feeding
*Bonding
Colostomy/Stoma Care
NEC - cause and effect
Development of babies with short bowel syndrome
Causes of prematurity
Responsibility of parents of premature/sick infant
*What is "normal"/what to expect (development) of the premature
Birth abnormalities
Effects of medications on premature baby
Association of birth weight and neurological development
How to stimulate intellectual growth in your child
How to encourage your child to be creative
Surgery - preparing young child for surgery
recovery
phychological effects
Effects of oxygen administration
Financial aspects of having premature/sick baby
Seizures
Administering medications to the newborn
Dealing with family/friends
Coping with "ups" and "downs" of baby's progress
Preparing for the birth of a premature/sick baby
Jaundice
Father's role
Care of premature twins
*Family relationships: husband/wife, siblings
Pyruvate Kinase Enzyme Deficiency
*Dealing with feeling of guilt, inadequacy
Prevention of prematurity
Explanation of equipment/procedures used in ICN
CPR and emergency procedures
*Cardiology/congenetal heart disease
Single parenting
Newborn and divorce
Imperforate anus
How to talk with your neonatologist

KF/kc
August 31, 1981

c. Developmental Guide for Parents. Central to the ICN Interact Project's intervention approach is assistance to parents in observing the infant's individual behaviors and interacting with the infant on the basis of those observations. The behavior of the significantly premature infant is dramatically different from that of the full-term baby which most parents expect.

Although education and interpretation are best done on an individual and continuing basis with parents at the infant's bedside, the number of parents for whom this can be provided is comparatively small. No guide to the behavior and development of the infant in the ICN, or to what the parent can do to aid development, is widely available. During the second project year a parent guide has been development in draft form which may extend the expertise of the project to parents in ICN's other than our own. The manual is described under Objective 6.

2) appropriate models and effective techniques for involving parents in the developmental follow-up of the high risk infant. Once the high risk infant leaves the ICN a new set of concerns faces both parents and the early intervention program which seeks to assist them. The task here is to identify approaches that, on the one hand recognize the special needs of the high risk infant, but on the other hand, do not minimize the infant's potential for normal development. The high risk infant may be more difficult for the parent to care for. Cues may be more subtle and endurance less than the healthy term baby. There may be recurrent medical crises. The baby may be irritable and difficult to soothe. Lengthy separation from the infant during the ICN stay may delay or alter the development of a basic parent-infant relationship. Infant development may be delayed and should be closedly monitored. Each of these problems may be lessened by appropriate intervention and follow-up once the baby goes home.

At the same time, the ability of the high risk infant to recuperate and develop normally must not be underestimated. It can happen that parents perceive their premature or critically ill newborn as chronically fragile or even handicapped. Inclusion in a special early intervention program can reinforce that perception.

Until some future time when infant development resources can be available to all new parents without labelling, early intervention with the high risk infant must take a different form from early intervention with the handicapped infant. It should be presented as preventative as opposed to remedial or therapeutic. Even more than with the parent of a handicapped infant the goal should be to reinforce the parent's individual child rearing skills and confidence rather than providing an educational program to be carried out.

During the second project year, several accomplishments have been made in the development of an effective follow-up model for parents of high risk infants. These include:

a. the development of a parent support group for ICN graduates.

b. preparation of a parent manual which deals with infant development and intervention during the transitional period after the baby goes home.

c. articulation of an individualized approach to follow-up. This is described in more detail under Objective 5.

3) satisfactory methods for evaluating project impact on participating parents. It may be as appropriate to assess project impact on parents as on infants. This is true if, as we believe, the parent is the primary developmental influence on the young infant.

A basic activity under Objective 3 is to guide parents in carrying out developmental activities with the infant in the ICN. But in ICN intervention we cannot merely be concerned with whether the parent carries out suggested developmental activities. Though this is one measure of project impact, it is not sufficient. The ICN is a crisis setting, in which parents get to know their infants for the first time, infants who are very different from what they expected. The infant educator can have a significant impact on the whole process. In order to assess this impact we need an assessment of parent-infant interaction in the ICN which can be correlated with later assessments of parent-infant interaction at home, and with the infant's developmental outcomes. Since a satisfactory instrument of this type does not exist, the project worked toward developing one, which was implemented in the first half of the second year. Outcome data will be included in the third year report.

The project has been successful in establishing during the first project year its role with parents in the ICN. Premature infants are being referred to the project at earlier points in their ICN stay, just so that the infant educators can begin work with the parents. Many of the infants referred before 31 weeks gestational age are too young and medically unstable for direct developmental therapy. However, the infant educator can begin work with the nurse (as discussed under Objective 2) and with the parent, who is in the critical early phases of forming a relationship with the baby, and needs support in the crisis of survival.

As was discussed under Objective 2, the ICN project has participated with nursing and other ICN staff in other accomplishments which should improve parent involvement with the high risk infant. These include the initiation of a parent support group and development of a parent room in the ICN. Project staff have supported the move toward primary care nursing, which is helpful to the parent, and more liberalized ICN visiting policies.

B. Slippages or Modifications of Objectives

There have been no slippages related to this objective. A minor modification has been made in deleting a parent questionnaire to be completed at the end of the ICN stay, in favor of a comprehensive questionnaire to be completed at the end of the first year of project participation. This questionnaire, completed when the infant returns for developmental assessment at one year, was implemented in the second project year as infants admitted in the first year reach that age. The final draft of the parent questionnaire is included in the Appendix. Results will be analyzed in the third year report.

Objective 4: To insure the provision of continued developmental therapy to all infants needing such care when they are transferred from the ICN at CHMC to secondary care nurseries.

A. Activities and Accomplishments

As originally proposed, the project was to follow infants transferred from the ICN for secondary care at two local nurseries. Referral patterns for secondary care and great interest in developmental intervention prompted expansion of secondary care follow-up to 4 community hospitals. Training in developmental intervention was provided for several additional hospitals for which greater follow-up involvement was not practical.

During the first year 12 infants were transferred to the 4 secondary care nurseries and received continued developmental therapy. However, as noted in the first year report, the average length of secondary care was much shorter than anticipated. Although a few babies remained longer, most received secondary care for only one to two weeks. The short stay limited the extent and significance of the follow-up developmental therapy program.

During the second project year the trend toward longer hospitalization in our tertiary ICN and then direct release to home continued and intensified. Only 9 of the 36 infants were transferred to secondary care nurseries, remaining 2 weeks or less, and often only a few day.

As discussed in Objective 2, training in developmental principles continued to be provided to nurses in secondary care nurseries. Five hospitals received training by the infant educators as a component of the Children's Hospital ICN Outreach Training Program.

B. Slippages or Modification of Objective

The trend toward less and shorter secondary care nursery stays for our ICN babies was identified in the first year and confirmed in the second. Consequently, a modification of the objective was made in proposing third year activities which reduce data collection and program resource allocations. Activities related to this objective were proposed on the then-current tranfer rate of more than 50% with an average stay of more than 2 weeks. Changes in patterns of intensive care no longer justify emphasis on model development and data collection in this area.

Objective 5: To provide coordinated developmental follow-up for infants who have received developmental therapy in the CHMC ICN upon discharge to home.

A. Activities and Accomplishments

Follow up was an area of particularly successful model development and accomplishments during the second project year. Activities include:

1) provision of follow-up services

2) establishment of a follow-up developmental clinic for all high risk infants leaving the ICN.

3) drafting of a description of the follow-up program model for replication purposes.

1) Provision of follow-up services. The developmental follow-up program has three major components:

a. home visits by project staff

b. quarterly neonatal follow-up clinic visits

c. coordination of other developmental examinations, services and referrals.

Home visits by project staff: Home visitng is initiated upon discharge of the baby from the ICN or secondary care nursery. The follow-up nurse is the primary provider of services in the home, though the infant educator who worked with the family in the ICN may also visit, particularly in the early weeks. In a few cases the infant educator may visit on a continuing basis with infants about whom there are identified developmental concerns. The follow-up nurse tailors the home visiting program to the needs of the specific family. Generally she attempts to make one visit as soon as possible after the baby is discharged and a total of two visits during the first month at home. She then attempts to visit monthly during the first six months, and every 2-3 months during the remainder of the year. A total of 113 home visits were made during a 10 month period by the follow-up nurse (no home visits occurred during a two month maternity leave).

Quarterly Neonatal Follow-Up Clinic visits: Once discharged to home, project participants begin a schedule of quarterly neonatal follow-up visits. During those visits they are seen by the follow-up nurse, developmental pediatrician and the infant educator who has worked with the family in the ICN. Assessments are also scheduled, if needed, by the physical therapist or nutritionist. The purpose to neonatal follow-up clinic is frequent monitoring of medical/developmental progress and current status, combined with developmental recommendations for the next few months. At 12 months of age the infant is tested by the project psychologist using the Bayley Scales of Infant Development.

Infant Performance on the Bayley Scales of Infant Development And Status at One Year Corrected Age

Infant #	Reason Not Tested at One Year	Mental Development Index (MDI)	Physical Development Index (PDI)	Referred to infant Program	Continued Follow-Up
1	Lost To Follow-Up				
2	Lost To Follow-Up				
3	Lost To Follow-Up				
4		50	63	x	x
5	Moved Out-Of-Area				
6	Died				
7	Died				
8		82	92		x
9	Lost To Follow-Up				
10	Lost To Follow-Up				
11		94	110		
12		84	110		
13		63	66	x	x
14	Lost To Follow-Up				
15		109	80		
16		115	98		
17		98	92		x
18		91	110		
19		98	86		
20	Moved Out Of State				
21		89	86		
22		112	86		
23		81	50	x	x
24		*	*	x	x
25		112	82		x
26		93	92		
27	Lost To Follow-Up				
28	Lost To Follow-Up				
29		109	92		x
30		54	52	x	x
31		96	*		x
32		115	98		
33	Lost To Follow-Up				
34		103	72		
35		106	80		
36	Scheduled Next Year				

* Bayley not administered due to sensory or physical deficits.

Any infant identified as having an emerging handicapping condition is referred to a more intensive early intervention program. The referral is coordinated by the follow-up nurse. To insure that the referral is effective, the project's developmental follow-up program contirues for all infants.

During the second project year a total of 106 neonatal follow-up clinic visits were accomplished. The low rate of missed appointments (21.5%) we attribute largely to the relationship with and assistance by project staff, particularly the follow-up nurse.

By the end of the second year, first year participants were reaching 12 months of age. At that time formal developmental assessments with the Bayley Scales of Infant Development are completed and a multidisciplinary case review and disposition occurs. Infants and families are referred to community resources as appropriate. If the developmental prognosis is uncertain, or if handicapping conditions are identified, the infant continues to be followed annually or even more frequently through the Child Development Center's core diagnostic services.

A total of 22 developmental assessments were completed by the end of the year on first year participants. One test was scheduled for completion after July 1st. Thirteen assessments were not completed because of death, the family moving from the area, or loss to follow-up - either becuase the family felt that the baby was doing well enough that further follow-up was not necessary, or, more frequently because family disruption (jail, mental illness, divorce, multiple changes of address) made a return for developmental purposes unimportant, impractical or both.

As can be seen from the table which follows, at one year corrected age most first year participants tested were functioning in the normal range. Several cautions must be noted in interpreting this data. First, for a number of these babies, particularly for those hospitalized for much of the first year, staff agreed that recuperation and health status were still developmental factors of unknown significance. Second, a growing body of research suggests that developmental scores in the first year may not be predictive of later performance of premature babies since milder handicaps may appear later. Third, developmental test scores do not reflect concerns with difficulties in the parent-infant attachment relationship and related delays in social, language and self-concept development. There were several families whose babies scored within the normal developmental range, but about whom we had significant concerns of this nature.

A total of 5 of these 23 infants, or 23%, were referred to early intervention programs for the handicapped. An additional 5 infants were scheduled for further developmental follow-up and assessment because of concerns about delays in specific developmental areas at one year corrected age. It is clear that this population is an appropriate one for preventative early intervention.

Coordination of other developmental follow-up examinations and services: As described in the first year report, the project pediatrician and particuarly the follow-up nurse, coordinate other services needed by the high risk infant during follow-up. Outreach services by the

nurse such as providing transportation or attending medical appointments with the family insure that needed assessments and services occur. All project infants are scheduled for vision and hearing tests during their first year of life.

The nurse also coordinates with the family pediatrian, medical specialists, social service personnel and public health nursing personnel who may be involved with the family. The family pediatrician is informed of every developmental concern and activity beginning with the ICN discharge summary by the infant educator, and continuing with the neonatal follow-up clinic reports.

2) Establishment of a follow-up developmental clinic for all high risk infants leaving the ICN. During the second year project staff advocated for, then helped plan and implement, a Neonatal Follow-Up Clinic for all high risk infants leaving the ICN. Prior to this, the only developmental follow-up available was that of the ICN Interact Project, which was limited to a small fraction of those infants in need of such services.

Neonatal Follow-Up Clinic, which utilizes partial funding available through California Childrens Services, is less frequent than that of the ICN Interact Project, but it does permit developmental monitoring during the first year of life. Infants are seen by a developmental pediatrician and a follow-up nurse at 6 and 12 months corrected age. It is hoped that changes in the funding mechanism also will permit some limited home visiting by the follow-up nurse, since home visiting has been found to be a significantly positive factor in ICN Interact Project follow-up.

3) Drafting of a description of the follow-up program model for replication purposes. A description of the follow-up program model has been drafted as proposed. The description includes intervention philosophy, home-based services, clinic based services and coordination with community resources. A copy of the description is included in the Appendix.

B. Slippages or Modifications of Objective

The project met or exceeded all timelines and proposed activities related to this objective. Establishment of a Neonatal Follow-Up Clinic was an unanticipated and particulary important accomplishment, which should benefit hundreds of high-risk infants leaving the ICN. There were no slippages or modifications of this objective during the second project year.

Objective 6: To prepare a handbook in developmental therapy for the parents of ICN patients.

A. Activities and Accomplishments

The preparation of a developmental guide for parents of premature and other new borns in the ICN was proposed as a major second and third year activity. The parent guide which has been named "Developmental Steps, a Guide For Parents To Infant Development In the Intensive Care Nursery" will be a major project of the ICN Interact Project.

All related activites have been accomplished as proposed. First and second drafts were completed in March and April. Late in the project year an unanticipated opportunity to have a content/editing review done by WESTAR, the technical assistance agency, hastened completion of a third draft.

The handbook emphasizes the parent's opportunities and role in assisting the development of their premature or seriously ill newborn. It emphasizes observational techniques as a basis for a parent's understanding of and interaction with their infant during and after the ICN stay. The parent handbook should fill an unmet need for a simple but informative guide to what the parent may expect of and do for the hospitalized newborn. A copy of the table of contents is included here.

B. Slippages or Modifications of Objective

The project met or exceeded all timelines and proposed activities related to this objective. There have been no slippages or modifications during the second project year.

DEVELOPMENTAL STEPS

A Guide For Parents To
Infant Development In The Intensive Care Nursery

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Objective 7: To prepare a training manual in developmental therapy and parent education suitable for health care staff in the ICN and other hospital nurseries.

A. Activities and Accomplishments

The preparation of a training manual for health care staff, like the parent manual described in Objective 6, was proposed as a major second and third year project activity. The manual was originally proposed to be completed in draft form by the end of the current project year, with completion and dissemination by the end of the third year.

Budget reductions for the second year necessitated elimination of the staff expansion planned to produce both the parent and health staff training, as well as to expand direct services. The staffing limitations required setting priorities among activities or originally proposed. After discussions with ICN personnel, project staff decided that a greater need existed for the parent manual than for the ICN staff training manual. No comparable resource existed for parents, but the EMI curriculum produced by an HCEEP project at the University of Virginia Medical Center offered developmental suggestions for the ICN. While the project proposed a different type of training approach, the parent manual was given a higher priority. In second year negotiations it was proposed and accepted that activities related to Objective 7 would largely be postponed until the third year.

While the parent manual was given higher priority, planning of the approach to training health care personnel did not cease. Original plans for a written manual were modified to include both written and audiovisual (slide-tape elements). This was based on discussions with ICN nurses about what the most effective presentation methods would be. Preparation for these elements began in more limited form during the second year.

B. Slippages and Modifications of Objective

Due to budget and staffing limitations in the second year, proposed activities realted to Objective 7 largely were postponed until the third project year. (see discussion above). Objective 7 will still be accomplished by the end of the project but in modified form. No slippages have occurred in working toward this modified objective.

Objective 8: To demonstrate the effectiveness of the ICN developmental therapy program so that other hospitals will start similar programs.

A. Activities and Accomplishments

Two types of activities fall under this activity 1) project evaluation, and 2) demonstration, dissimination and replication activities.

1) Project Evaluation: Evaluation of project effectiveness is particularly challenging in this new area of intervention with premature and other seriously ill newborns. Some of the issues were discussed in the first annual report. Briefly, they include the lack of developmental assessment techniques; the unpredictability of later developmental outcomes from either neonatal risk factors or developmental assessments in the first months of life; and the variable and unknown impact of unstable medical conditions during this period.

It was clear from the beginning of the project that innovations in the evaluation area would be needed. A significant focus of the ICN Interact Project has been the development,and implementation of appropriate evaluation approaches. The challenge is even greater because the critical care environment of the ICN and the fragile health status of ICN babies preclude any non-essential assessment procedures.

The evaluation plan calls for an examination of project impact in four major areas:

a. infant development

b. parent involvement

c. ICN nurse involvement

d. ICN ecology and discharge procedures.

The evaluation plan has been implemented as described in the first annual report. Several additional modifications occurred during the second project year, in the area of infant assessment and parent assessment.

a. Infant assessment modifications: Project evaluation procedures have evolved each year of the project, as technical assistance through WESTAR has been obtained from noted authorities on work with premature infants. In the first year several evaluation procedures were developed with the assistance of Dr. Peter Gorski of Mr. Zion Hospital in San Francisco. These were described in the first annual report.

Late in the first year project staff learned of an assessment of premature infant behavior under development by Dr. Heideliese Als at Harvard University (this and other assessments are discussed under Objective 1 in this report). Project staff determined that this would provide the most detailed infant assessment for evaluation and clinical purposes. They began use of the APIB in November and were evaluated in assessment procedures by Dr. Als during a 3 day site visit in March.

The APIB was adopted for use as the primary infant assessment procedure, replacing the modified Brazelton assessment and developmental observation procedures used earlier.

b. Parent assessment modifications: In addition to refinements of infant assessment procedures, the project also developed parent assessment procedures as proposed during the second year. What was needed was an assessment of parent-infant interaction which could be initiated in the ICN but then continued during the first year at home. To that end project staff combined key ICN interactional observation items with earliest items on the Parent Behavior Progression, developed by Dr. Rose Bromwich, et.al. This assessment procedure was developed, revised and implemented in the second project year as proposed, as was a parent evaluation questionnaire.

Late in the third project year additional technical assistance was provided by WESTAR in the evaluation area. The purpose was to develop an evaluation strategy which could cope with the changes in assessment procedures and resultant data. Several promising ideas were under development at the end of the second project year and beginning of the third. These included pooling data on key infant behaviors common to all assessment procedures and also examining best/worst outcome groups retrospectively. Details of the final data analysis plan will be included in the interim report.

2) Demonstration, Dissemination, Replication and State and Federal Involvement.

A. Activities and Accomonplishments

Major demonstration, dissemination and replication activities have been accomplished as proposed. As in the first year, accomplishments in these areas have exceeded original expectations. Furthermore some activities, particularly at the state and federal level were of significance to services to high-risk and handicapped infants in general.

Demonstration

Visitors: Because of the nature of the project's setting in the ICN, on-site visitors are restricted to those planning to initiate or improve developmental intervention programs for high-risk infants. A total of 30 visitors were scheduled on-site, of whom approximately 1/3 were taken into the ICN for actual demonstrations of developmental assessment and intervention techniques. For the remainder discussion with different staff members and examination of project materials met demonstration purposes.

Presentations: Project staff made presentations at four local meetings and regional conferences, to a total of approximately 185 nurses, educators, physicians, administrators and decision makers.

A significant demonstration activity was the presentation by Dr. Heideliese Als at Children's Hospital Grand Rounds and at a special invitational luncheon meeting. Dr. Als presented on the assessment of premature infant behavior, and on the theroy and observations in this area which support the value of developmental intervention beginning in the ICN.

Grand rounds at Children's Hospital generally attract 50 or more pediatricians and medical specialists in the East Bay area. Special announcements were distributed by the ICN Project to interested professionals from neighboring ICNs and community agencies serving young children. More than 100 people attended the grand rounds presentation.

At a special invitational luncheon presentation, Dr. Als continued in greater detail with the developmental perspective. The presentation was attended by 35 relevant professionals, including neonatologists, nurses, therapists, CDC staff and several professionals from neighboring ICNs.

Project staff also contributed to two books by parents and for parents of premature babies, one of which was just published, the other of which will be published late in the year. Developmental consultation was provided to the authors of both books.

Dissemination

Project Brochure: Approximately 150 copies of the project brochure have been distributed to visitors, at conferences and in response to requests for information.

Articles: Project staff have produced three chapters on intervention with high risk infants. Two of these three chapters were based on conference presentations, which also were summarized in a Conference Proceedings published by WESTAR.

The chapter titles included:

-"Humanizing the Intensive Care Nursery Environment"

-"New Faces and Approaches in the ICN: The Role of the Developmental Specialist"

These two chapters appear in "Issues in Neonatal Care" to be published soon by WESTAR. The third chapter appears in "Curriculum Materials For High-Risk and Handicapped Infants", to be published by TADS. This chapter is:

-"Intervention With the Very Youngest: Curricula For High-Risk and Developmentally Disabled Young Infants"

Media: A summary of an earlier newspaper article "Humanizing the ICN" was published in the national magazine "Children Today". Many requests for further information continue to be received as a result of that article.

The project also was discussed during an hour long radio show "Special Education For Babies" presented by San Francisco radio station KNBR.

Replication

Replication was not proposed as a significant second year activity, but preparation of materials for replication purposes was accomplished as proposed. Drafts of replication packet materials,

the parent manual and other materials were completed for revision and use in the final year of the project.

During the year three extensive site visits were made by personnel from other ICNs in the state (2) and out of state (1). The purpose of the site visit was to learn about and replicate project procedures.

Two of the chapters which were completed during the year were written as replication guides for other professionals in the ICN. One chapter described the role of the developmental specialist in the ICN while the other described intervention goals and techniques.

State and Federal Involvement

Significant and unanticiapted accomplishments occurred in the stimulation of improved services to high risk and handicapped infants. This was achieved by particiaption in regional,state and national advisory committees and task forces concerned with services to young children with special needs. These included:

State Level: State Implementation Grant Advisory Committee, Office of Special Education. Legislation mandating services to handicapped infants was introduced as one result of committee member activities. Although the mandate was defeated when its proposed funding mechanism was defeated, a state advisory committee, The Ad Hoc Committee on Early Intervention, was established by the legislation to report to the Governor, legislature and state agencies on services to infants.

Infant Systems Development Committee, State Council on Developmental Disabilities. This committee was convened to identify services and unmet needs of disabled infants. It succeeded in encouraging the State Council on Developmental Disabilities to recognize services to infants as one of its three planning priorities for the coming year.

Advisory Committee on Young Children With Exceptional Needs, Commission on Teacher Preparation and Licensing. Several years of committee work on an Early Childhood/Special Education Teaching Credential culminated in a completed competency-based credential description, public hearings and introduction to the legislature as part of a larger credential bill. Unfortunately the entire bill was defeated, but there are hopes that this credential can be introduced in a new piece of legislation in the coming year.

California First Chance Consortium. The consortium of HCEEP projects continued to work on behalf of services to young children with special needs. Membership was expanded to include other leaders in the state. The consortium worked to support special education in general and specifically legislation mandating services statewide to handicapped infants. The director of the ICN Interact Project agreed to act as legislative liason for the First Chance Consortium and to be active in involving newly forming infant networks in consortium activities.

Federal Level: INTERACT. The project director was pleased to participate in initial drafting of the forthcoming monograph on professional competencies for work with infants with special needs and their families. The monograph should be extremely useful not only to students, training institutions and program developers, but also to states considering credentials and professional standards in this new area.

B. Slippages or Modifications of Objective

There were no slippages or modifications of this objective. All proposed timelines and activities were met or exceeded. Participation in state and federal advisory committees and task forces has and should result in benefits beyond the project's immediate target area and groups.

Objective 9: To demonstrate the effectiveness of the ICN developmental therapy program so that continuation funding may be obtained.

A. Activities and Accomplishments

Efforts to obtain continuation funding were proposed as a primary activity during the final project year. However, during the second project year efforts to insure continuation of the second model component, developmental follow-up services, were successful.

An ongoing neonatal follow-up clinic was established to follow all infants meeting certain risk criteria when they leave the ICN. Though the services of the Neonatal Follow-Up Clinic are not as frequent or as effective (e.g. no home visiting) as project follow-up services, they are available to more of the babies who need to be followed. There is hope that modification of the funding mechanisms at the state level may enable appropriate components such as home visiting to be added in the near future.

During the final year continuation funding therefore needs to be sought only for the first model component, which is developmental intervention in the ICN. However, as described in preceding reports, continuation funding for this component will be a challenge. The educator is a new role in the medical setting and particularly in the ICN. There are neither professional standards nor funding mechanisms for this role in California. From the beginning of the project it was recognized that continuation would require major advocacy and perhaps legislative efforts.

Active participation in the second year in several advisory committees on services to infants was seen as essential to securing continuation for the ICN intervention component. By identifying umet needs of the high risk infant population, as well as new opportunities for early identification and intervention, it was hoped that ongoing state funding could eventually be obtained. There is growing interest by both the Department of Health and the Department of Developmental Services, in the high risk infant. Legislation has just been passed which will permit preventative services to high risk infants through the Regional Center system. Although a specific funding method was not achieved during the second year, the climate will be moderately favorable to such efforts in the final year, to the extent that the state's current economy permits.

B. Slippages and Modifications of Objective

There have been no slippages or modification of this objective. Project timelines have been exceeded by one year by obtaining continuation of one of the project's two component services, developmental follow-up, in the second year. Developmental follow-up also will be available to larger numbers of high risk infants than the project was able to serve.

III. UNANTICIPATED SPIN-OFF BENEFITS

The ICN Interact Project continued to be as successful in meeting and exceeding project objectives in its second year as it was in its first. Pilot work, an expert staff and the support of other professionals in the ICN have enabled the project to achieve significant progress both within and beyond original objectives. In addition to achievements related to project objectives, several unexpected achievements and benefits can be identified.

1) unanticipated benefits to infants, parents and ICN staff. These have resulted from:

a. developmental services requested and provided for 41 non project babies, in addition to the 72 project babies.

b. participation in the development of an ongoing support group for parents of premature babies from Children's ICN.

c. participation in the design of a new, more developmentally appropriate ICN which will be opend in the fall of 1982.

d. participation in the initiation of an ongoing Neonatal Follow-Up Clinic, which will provide developmental services to many high risk infants leaving the ICN.

2) unanticipated demonstration and dissemination opportunities and products. Of particular note is the preparation of three papers for inclusion in two forthcoming monographs. Not only will these be useful for replication purposes, they provide a means of general education of personnel in other medical settings as well. Developmental intervention and even concern in the ICN is a new focus for many medical professionals who may be able to influence developmental factors in the ICN once they are aware of those factors.

3) unacticipated opportunities to contribute to improvements in statewide services to infants with special needs. Through participation in a number of committees and task forces a number of actions have occurred which should result in improved services. These include several committees concerned with quality availability and interagency coordination of services to infant; several committees concerned with professional competencies and standards in the infancy area; and culminating legislative, regulatory and policy initiatives. Though not all initiatives have been successful yet, the significant unmet developmental needs of infants in California have been brought to the attention of the Governor, legislature, related state agencies, and state level advisory groups.

IV. ADVISORY COMMITTEE

During the second project year the Advisory Committee meet as proposed. Several new parent members were added during the year. Late in the year plans were made to expand the size and scope of the Advisory Committee for the third and final year of the project. The list of Advisory Committee members prior to the expansion is included here.

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APPENDIX

- Sample Infant Assessment,
  using the Assessment of Premature Infant Behavior (APIB)
- Parent Questionnaire
- Description of Follow-Up Model
- ICN Interact Conference Agenda:
  The ICN: Intervention and Follow-Up

ASSESSMENT OF PRETERM INFANT BEHAVIOR

(APIB)

NAME: R Desiree 5/26/82

DOB: 3-16-82 28wks

AGE: 6wks. CORRECTED AGE: 24wks

INITIAL STATE: 4 or 2-3 PREDOMINANT STATE: 3-4 to 4-6

INTERFERING VAIABLES: LCA

PACKAGES COMPLETED AND ORDER: 1, 2, 3, 6, 4, 5

SYSTEMS SCORING:

Physiology: Moderate to considerable respiratory unevenness & some lapses in pkg I & considerable facial twitches. In pkg VI as bc alerted his respiratory unevenness improved, color improved, floating eye movements & some tracking present. Moderate to big lightness & pink color returned & pkg V.

Motor: Moderate flexion & moderate extension protecting. Some brief periods of modulated flexion & sudden abrupt changes. Jerky movements & some directed hand effort to track alternating flexion & extending. Pkg 3-4 increased postural control.

State: Maintained state 2a throughout pkg 1, 2, 3 & aroused to 4b + in pkg 6, 4, 5 maintained 4b. Duration of 4b is impressive & baby was available for some brief periods of social interaction.

Attention/Interact: Moderately variable attention & some diffuseness during social interaction. Some brief modulated attention embedded in diffuseness.

Regulatory: In pkg 1, 2, 3 she made repeated efforts to return to balance some of which were successful but many not & there was a great deal of disorganized thrashing & motor diffuseness. In pkg 6, 4, 5 she was interested & in alertness & successfully most of the time & some motoric arousal during stimulation

Environ. Facilitation: During pkg 1, 2, 3 moderate facilitation needed & repeated time outs. In pkg 6, 4, 5 mild only needed in form of bracing, hand holding & slow pacing.

PACKAGES AND MANEUVERS:

Package I: (sleep-distal)

Light: No shut down. Body & head movement still present after 10 trials. Brief initial response - eye blink, mild recycling, repeated disorganization & motor

Little: No shutdown. Hand-body movement still present after 10 trials. Some brief initial during between trials response & recycling but repeated disorganized reactions in between & mild motor

Full: X during after 10 trials

Package II: (sleep prone/supine)

Uncovering and Turning:

Uncovered & great care & moderate disorganization in movements (diffuse) returned once & mild recycling. But she achieved & carried & regained control on her own. KJ

Package III: (low tactile maneuvers)

Fine Feet/Hands: N

Heel Touch: X

Plantar Grasp: R weak L ok Babinski: R weak L good

Clonus: R 3beats L 0beats Palmar Grasp: R weak L weak

Pull. Grasp: weak mouth opening + hand-grasp on one side R only

Passive Movement:

Arms: Good resistance R good recoil L good recoil Legs: Good resistance R good recoil L good recoil

Arm/Leg Differentiation: good Glabella: good

Rooting: good on L not on R Sucking: not assessed

Package IV: (medium tactile/vestibular maneuvers)

Undress: N

Pull to Sit: resting brought head up + did not maintain but tried to hold it

Standing: no umbrella - good wt bearing Walking: no response

Placing: weak R L weak Incurvation: good

Crawl: no response - when put down, no movement - extended legs "frog"

Cuddling: hunches + nestles when held + turns toward body being held + leaves in shoulder no fetal tuck

Tonic Neck Reflex: weak R L weak

Defensive Reaction: calm to alley - shows non-directed avoidance of arms

Package V: (high tactile/vestibular maneuvers)

Rotation: weak head turn to L, none to R, no reaction of eyes.

Moro: Weak arm extension + exaggerated adduction. Good leg extension + relaxation prn

Package VI: (attention/interaction) Alert + Recount

Face and Voice: Focused followed 30° arc, jerky movements + Strong effort to attend alternating + strong effort (sneezing, squeaking, sneezing) not to. Mild cost + Modulated quality - no flatness or huffiness/tiredness heresy.

Face:

Still, focused, brief following + all of above

Voice: stills, brightens, quiets, no orienting + all above

Red Rattle: stills, brightens, focuses + follows briefly - all above

Red Ball: focuses + follows brief segments - all above

Bell: stills, quiets, made attempt to orient - all above

BEHAVIORAL SUMMARY SCALES: (continued on next page)

ASSESSMENT OF PRETERM INFANT BEHAVIOR/con.

[redacted]:

BEHAVIORAL SUMMARY SCALES:

Physiological Parameters:

Stimulousness: 8 or more times in state 4 + mild tactile

Startles: only a few

Skin Color: Initially good, gets worse but recovers well

Spikes: Spiked ventricular beats in sleep only

Motor Parameters:

Tonus: variable hyperextends, hyperflexes resting - responsive 75% of time as handled

Motor Maturity: Quite immature mild overshooting - becomes imbalanced at ht distal flexion moderately poor total neck + body tone, diff of flexion + extension balance. At pole weaker - continuous active withdrawal is rarely available

Hand to Mouth: Infrequent - no real contact.

State Parameters:

Alertness: Min alert responsivity brief, not delayed, variable, available + manipulation Good bright alert focused for brief periods - face eyes + responds spontaneously for prolonged period

State Regulation: Keep asleep in 4th w minimal aggravation to 5 a indicating mild - moderate stress

Self Regulation Parameters:

Avoidance Behaviors: throw cough, grimace, finger splay, salute, sneeze, yawn, averting

Approach Behaviors: tongue extension, hand on face, sounds, suck, body movement hand to mouth, grasping, left face, mouthing, neck search, suck, both face, locking

Quieting: limited self quieting from motoric arousal. If intervention needed responded well to restraining arm + hand on belly

Peak of Excitement: Excellent motoric arousal but predominantly to ht

Rapidity of Build-Up: motorically aroused only - no fuss or cry to being placed in supine

Irritability: No irritable crying or systemic fuss or primed upset to any stimulation except defensive maneuvers - startle!

Robustness: Shuts out bright but improves in time able to receive visual + tactile stimuli

Control over Input: Good control over strong stim - showed considerable yawning

Facilitation Stimulation: Appears interested in alertness at ht + face + hand mild motor response to tap of nasally stayed but together own - is available for examination.

Summary Attractiveness:

Can be brought to a nice prolonged alertness + some brief alerts of social interaction.

IMPRESSIONS: A premie who seemed very disorganized at 1st but + state changes, and consistent handling + time limit cues came into a prolonged alert period during which she was available for brief orienting periods. Rt side was consistently less responsive than left.

Recommendations: 1) Gently encourage arousal to alertness as she wakes up.

2) offer face + voice slowly one at a time + then together to encourage orienting.

3) Position + ft to midline, back supported when on side

4) Position in prone + hand to mouth.

Examiner T. VanDenBerg date 5/26/82

ASSESSMENT OF PRETERM INFANT BEHAVIOR (APIB)

H. Als, Ph.D.
B.M. Lester, Ph.D., E. Tronick, Ph.D., T.B. Brazelton, M.D.

© February 1979

INFANT'S NAME	MED. REC. NO.	DATE OF BIRTH	AGE (Post-conception)
R. Deaver			28 wks

TIME – LAST FEEDING	TYPE OF FEEDING	CURRENT INTERVAL BETWEEN FEEDS
12:00	nipple	3 hrs 34 wks corrected 6 weeks Rel

INITIAL CIRCUMSTANCES OF INFANT

POSITION	☐ SUPINE	☑ PRONE	☐ SIDE	
HEAD	☐ RIGHT	☑ LEFT	☐ MIDLINE	
COVERING	☐ DIAPER	☐ SHIRT	☐ CLOTHES	☐ BLANKET(S) none in bed

INFANT'S INITIAL STATE	INFANT'S PREDOMINANT STATE
2a Hal-2a	2a & 4b

WEIGHT	HEIGHT	HEAD CIRCUMFERENCE	PONDERAL INDEX
____ LBS ____ OZS ____ GMS	____ INCHES ____ CM	____ INCHES ____ CM	

DATE OF EXAM	TIME OF EXAM	PLACE OF EXAM	PERSONS PRESENT
5/24/82	2 pm	DCN	☐ MOTHER ☐ FATHER ☐ SIBLING(S) ☐ OTHER Nurse

INTERFERING VARIABLES	EXAMINER	VIDEO	DURATION OF EXAM
H-5	KD		1 hr

SCORE SHEET I – SYSTEMS

LEGEND: B = Baseline R = Reaction P = Post-package Status

	ORDER OF PKG	PHYSIOLOGY B	PHYSIOLOGY R	PHYSIOLOGY P	MOTOR B	MOTOR R	MOTOR P	STATE B	STATE R	STATE P	ATTN/INTERACT B	ATTN/INTERACT R	ATTN/INTERACT P	REGULATORY B	REGULATORY R	REGULATORY P	EXAM FACIL
PACKAGE I BLEEP/DISTAL	1	5	6	6	5	6	6	4a/2	2a/2	2a/2				4	6	5	4
PACKAGE II UNCOVER/SUPINE	2	6	6	5	6	6	6	2a/2	2a/2	2a/3	3a			5	6	5	4
PACKAGE III LOW TACTILE	3	5	6	6	6	7	7	2a/2	4b/1	4b/1				5	3	3	3
PACKAGE IV MEDIUM TACTILE/VESTIBULAR	5	4	5	6	6	7	7	4b/1	4b/2	4b/1				2	3	3	3
PACKAGE V HIGH TACTILE/VESTIBULAR	6	6	6	6	6	6	6	4b/1	4b/2	4b/1				3	3	3	3
PACKAGE VI ATTENTION/INTERACTION	4	4	3	4	6	6	6	4b/1	4b/2	4b/1	6	6	6	3	2	2	3

COMMENTS:

Avoid
4a
4b
3

SCORE SHEET II – PACKAGES AND MANEUVERS

								ORDER
I: SLEEP/DISTAL LIGHT	Decrement 5	BNBAS 3	Ease of Elicitation 6	Timing 9	Recycling 2	Disorganization 8	Discharge 5	
RATTLE	Decrement 5	BNBAS 3	Ease of Elicitation 8	Timing 9	Recycling 1	Disorganization 8	Discharge 4	
BELL	Decrement N	BNBAS	Ease of Elicitation	Timing	Recycling	Disorganization	Discharge	
II: SLEEP PRONE/SUPINE UNCOVER	Capacity to deal with N →							
PRONE TO SUPINE	Capacity to deal with 3 →							
III: LOW TACTILE FREE FEET/HANDS	Capacity to deal with N →							
HEEL TOUCH	BNBAS X	Ease of Elicitation –	Timing	Recycling	Disorganization	Discharge →		
PLANTAR GRASP	BNBAS/R 1	BNBAS/L 2 →						
FOOT SOLE STROKE (Babinski)	BNBAS/R 1	BNBAS/L 2 →						
CLONUS	BNBAS/R 2	BNBAS/L 0 →						
PALMAR GRASP	BNBAS/R 1	BNBAS/L 1 →						
PALMAR MENTAL GRASP	APIB 1 →							
PASSIVE MOVEMENT ARMS	Resistance R 2	Resistance L 2	Recoil R 1	Recoil L 2	BNBAS/R N	BNBAS/L N →		
PASSIVE MOVEMENT LEGS	Resistance R 2	Resistance L 2	Recoil R 2	Recoil L 2	BNBAS/R 2	BNBAS/L 2 →		
ARM/LEG DIFFERENTIATION	APIB 2 →							
GLABELLA	BNBAS 2 →							
ROOTING	BNBAS/R 20	BNBAS/L 2 →						
SUCKING	BNBAS X →							

SCORE SHEET II – PACKAGES AND MANEUVERS (Continued)

								ORDER
IV: MEDIUM TACTILE/ VESTIBULAR								
UNDRESS	Capacity to Deal With: N →							
PULL TO SIT	BNBAS: 4	Hyper-extension	Hyper-flexion →					
STANDING	Umbrella: N	BNBAS: 2 →						
WALKING	Umbrella: N	BNBAS: 0 →						
PLACING	Umbrella R: N	Umbrella L: N	BNBAS/R: 1	BNBAS/L: 1 →				
INCURVATION	BNBAS/R: 2	BNBAS/L: 2 →						
CRAWL	APIB: 0	BNBAS: 0 →						
CUDDLING	Vertical: 5	Fetal Tuck: 1	Horizontal: 5	Fetal Tuck: 1	BNBAS: 8 →			
TONIC NECK REFLEX	BNBAS/R: 1	BNBAS/L: 1 →						
DEFENSIVE REACTION	BNBAS: 1 →							
V: HIGH TACTILE/ VESTIBULAR								
ROTATION	Head R: 0	Head L: 1	Eyes R: 0	Eyes L: 0	BNBAS/R: 0	BNBAS/L: 1	Nystagmus: 0	
MORO	Arms Extension: 2-3	Arms Adduction: 3	Legs: 2	BNBAS: N →				
VI: ATTENTION/ INTERACTION								
ANIMATE VISUAL & AUDITORY (Face&Voice)	Elicitation Maintenance: 3	Orientation (E): 4	Orientation (A): N	Effort: 5	Cost: 4	Quality: 7 →		
ANIMATE VISUAL (Face)	Elicitation Maintenance: 3	Orientation (E): 3	Orientation (A): N	Effort: 5	Cost: 4	Quality: 6 →		
ANIMATE AUDITORY (Voice)	Elicitation Maintenance: 4	Orientation (E): 4	Orientation (A): N	Effort: 5	Cost: 4	Quality: 6 →		
INANIMATE VISUAL & AUDITORY (Rattle)	Elicitation Maintenance: 4	Orientation (E): 3	Orientation (A): N	Effort: 5	Cost: 4	Quality: 6 →		
INANIMATE VISUAL (Ball or Rattle)	Elicitation Maintenance: 4	Orientation (E): 3	Orientation (A): N	Effort: 5	Cost: 4	Quality: 6 →		
INANIMATE AUDITORY (Rattle)	Elicitation Maintenance: 4	Orientation (E): 4	Orientation (A): N	Effort: 5	Cost: 4	Quality: 6 →		

BROOKE SHEET III – BEHAVIORAL SUMMARY SCALES

PHYSIOLOGICAL PARAMETERS

TREMULOUSNESS	BNBAS: 6			
STARTLES	BNBAS: 2			
SKIN COLOR	Lability of Basal Color: N	Lability of Comp Color: 1	Threshold: 9	Jaundice: 1
SMILES	APIB: 4	BNBAS: 3		

MOTOR PARAMETERS

TONUS	BNBAS: 6	Balance: 8		
MOTOR MATURITY	BNBAS: 2	Threshold: 8	Postural Control: 5	Symmetry: 4
ACTIVITY	Spontaneous Activity: 5	Elicited Activity: 5	BNBAS: 4	
HAND-TO-MOUTH FACILITY	BNBAS: 2			

STATE PARAMETERS

ALERTNESS	Degree (B): N	Degree (A): 4	Quality: 6	Am't. Manipulation: 3	STATE REGULATION	Lability: 4	Range and Flexibility: 7	BNBAS: 3	

SELF REGULATION PARAMETERS

WITHDRAWAL OR AVOIDANCE BEHAVIOR

CATALOG OF REGULATION MANEUVERS

Spit-ups: 0	Gags: 0	Hiccoughs: 1	Bowel Mvt: 0
Grimace: 2	Arching: 0	Finger Spray: 1	Airplane: 0
Salute: 2	Sitting on Air: 0		
Sneezing: 1	Yawning: 2	Sighing: 0	Coughing: 0
Averting: 2	Frowning: 0		

APPROACH OR GROPING BEHAVIOR

CATALOG OF REGULATION MANEUVERS

Tongue Extension: 1	Hand on Face: 1	Bounds: 1	
Hand Clasp: 0	Foot Clasp: 0	Fingerfold: 0	Tuck: 3
Body Movement: 3	Hand to Mouth: 2	Grasping: 1	Leg/Foot Bracing: 1
Mouthing: 3	Suck Search: 1	Sucking: 1	Hand Hold: 0
Ooh Face: 1	Looking: 1	Cooing: 0	

QUIETING	Self-quiet ↓ B: N	Self-quiet Motor ↓: 6	Consolability ↓ B: N	Consolability Motor ↓: 7
PEAK OF EXCITEMENT	BNBAS: 4			
RAPIDITY OF BUILD-UP	Rapidity ↑ B: N	Rapidity ↑ Motor: 7		
IRRITABILITY	Irritability (B): N/A	Irritability (A): 3.2		
ROBUSTNESS	Robustness: 2.5			
CONTROL OVER INPUT	Control Over Input: 6-7			
FACILITATION STIMULATION	Facilitation Stimulation: 7			

SUMMARY ATTRACTIVENESS: 8

SYSTEM ORGANIZATION GRAPH (APIB)

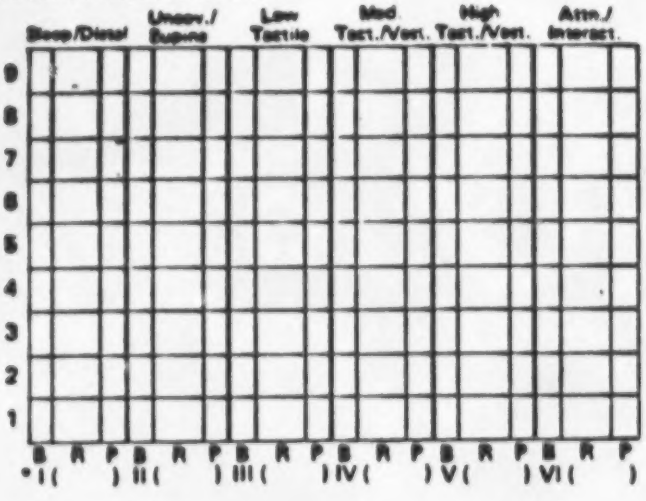
From SCORE SHEET II

H. Als, Ph.D.
B.M. Lester, Ph.D., E. Tronick, Ph.D., T.B. Brazelton, M.D.

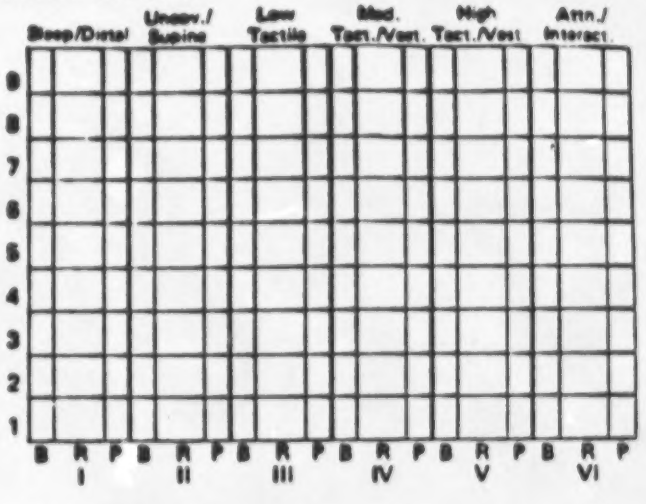
© February 1979

INFANT'S NAME _____ MED. REC. NO _____ DATE OF EXAM _____ AGE (Post-conception) _____

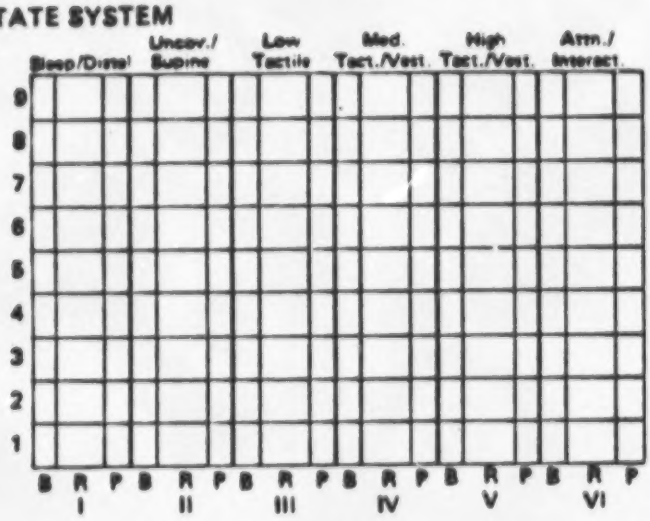
PHYSIOLOGICAL SYSTEM


Bloop/Distal
Uncov./ Supine
Low Tactile
Med Tact./Vest.
High Tact./Vest.
Attn./ Interact.
9 8 7 6 5 4 3 2 1
B R P B R P B R P B R P B R P B R P
I ( ) II ( ) III ( ) IV ( ) V ( ) VI ( )

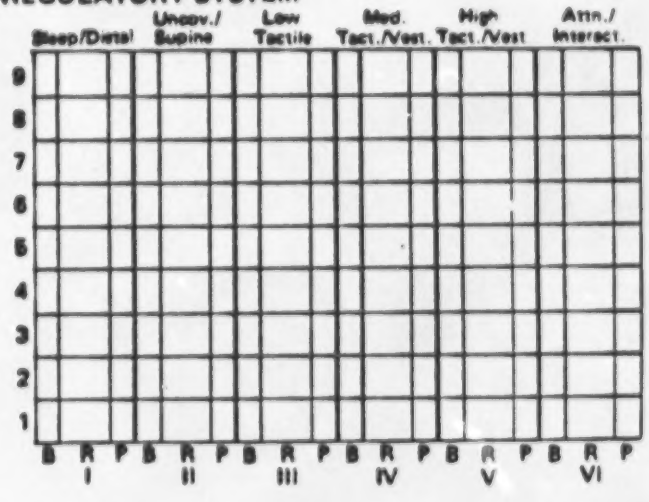
MOTOR SYSTEM


Bloop/Distal
Uncov./ Supine
Low Tactile
Med. Tact./Vest.
High Tact./Vest
Attn./ Interact.
9 8 7 6 5 4 3 2 1
B R P B R P B R P B R P B R P B R P
I II III IV V VI

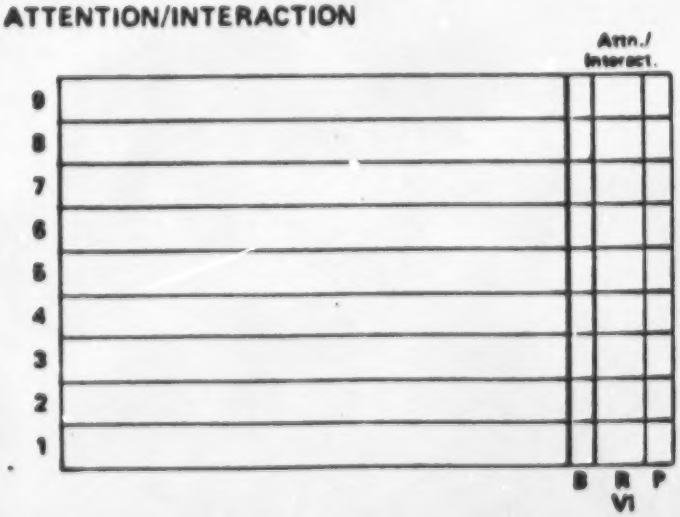
STATE SYSTEM


Bloop/Distal
Uncov./ Supine
Low Tactile
Med. Tact./Vest.
High Tact./Vest.
Attn./ Interact.
9 8 7 6 5 4 3 2 1
B R P B R P B R P B R P B R P B R P
I II III IV V VI

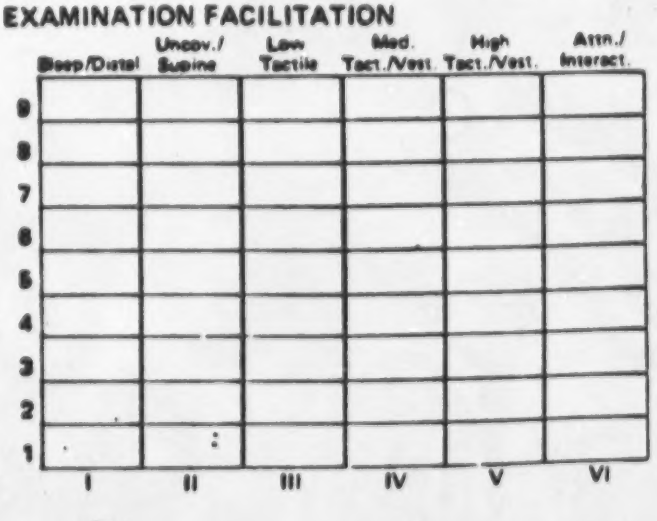
REGULATORY SYSTEM


Bloop/Distal
Uncov./ Supine
Low Tactile
Med. Tact./Vest.
High Tact./Vest
Attn./ Interact.
9 8 7 6 5 4 3 2 1
B R P B R P B R P B R P B R P B R P
I II III IV V VI

ATTENTION/INTERACTION



EXAMINATION FACILITATION



SUPPLEMENTAL LIST OF ASYMMETRIES

Check, rate degree and describe asymmetries noted; rate degree of asymmetry on a 0 – 3 continuum.

0 = no asymmetry noted (the item was not checked)
1 = subtly & mildly present and/or very transient
2 = moderately pronounced and/or intermittent
3 = pronounced, strong

Asymmetries	Check	Degree	Side	Description
1. Arm	___	mod	mod	record Rt arm
2. Hand	___	___	___	___
3. Fingers	___	___	___	___
4. Leg	~~Leg~~	Rt	flexes less than left -	
5. Foot/Toes	___	mod	plantar flx Rt > mod Babinski	
6. Trunkal Posture	___	___	___	___
7. Head Positioning	___	___	___	___
8. Face	___	___	___	___
9. Eyes	___	___	___	___

Comments:

CHILDREN'S HOSPITAL MEDICAL CENTER

TREATMENT AND FOLLOW-UP RECORD

DATE	Assessment of Preterm Infant Behavior (APIB)
Speech	Baby R. ___ was evaluated to determine her ability to handle stimulation and begin social interaction. The following is a highlighted summary of findings + recommendations. Completed exam is available from Kathy VandenBerg Child Development Center ext 3351.
	Initially baby R ___ was in a light sleep state and the maneuvers of package I, II + III were successfully carried out. She awoke to a nice prolonged spontaneous alert state which she maintained throughout the demands of packages IV V + VI. The following highlights her responses + abilities:
	1) Physiological parameters during stimulation:
	Moderate to considerable respiratory unevenness + some cyanosis observed throughout sleep states + considerable body twitching. As she alerted, respiratory status improved, color improved. As handling became more vigorous poor color + respiratory irregularity returned.
	2) Motor Responses: Predominantly maintains a posture alternating between moderate flexion + some hyper-extension + some brief periods of good control. Jerky movements + some palsies. Tone varied between hypertension + hypotonia.

DATE

some asymmetries noted in that rt side was weaker in plantar, Babinski, palmar + arm recoil. left side good in these responses. All other reflex responses were good except placing which was weak.

3) Attention/Interaction: maintained good alert period + brief periods of responsivity to face, rattle, red ball. Tracked at most + 30° and reacted to auditory stimulus but did not orient. face softens when attentive but for very brief period. Quality of attention varied from bright eyed focused attention + strong efforts to attend to strong efforts to not attend indicating mild stress in form of yawns, sneezes and averting.

4) Consolidation: Never became irritable but did arouse and almost fuss + active motor arousal to strong stimulation from which she successfully calmed herself. When intervention became necessary placing hand on her chest holding her arms, she calmed readily.

5) Self Regulation: throughout exam makes strong efforts successfully to control herself and maintain a balance. At times she is successful and at times not. In deep states she appeared disorganized but in alertness she was more successful.

Impression: Baby R is demonstrating decreasing stress to handling while increasing her ability to regulate her own states and is beginning to become responsive. Stress reactions noted with alert periods. Alertness is of good quality + duration but she is not yet able to orient or respond to related social interaction. Rt side weaker than left + needs stimulating. Work + parents to encourage entree interaction. K VandenBerg Infant Clinic

EDC 41335

Children's Hospital Medical Center
of Northern California

51st and Grove Streets / Oakland, California 94609 / (415) 428-3000

Dear Parents:

As parents of a baby who has been in Children's Hospital Intensive Care Nursery, and as participants in the ICN Interact Project, we need your help. We would like your views and comments in order to improve the ICN experience for other parents. We need your evaluation of how helpful our ICN Interact Project has been to you and your baby.

Enclosed is a short evaluation form which we would like you to complete and send back to us as soon as possible. We need an evaluation by each family participating in the program. If you would prefer, the form can be completed by phone by calling Diane Valentin at 428-3351.

Thank you for your help.

Best wishes,

The ICN Interact Project

enc.

Children's Hospital Medical Center
of Northern California

51st and Grove Streets / Oakland, California 94609 / (415) 428-3000

WHAT DOES THE ICN INTERACT PROJECT PROVIDE FOR FAMILIES?

In the ICN

The infant educator, Kathy VandenBerg or Bette Flushman, works with the baby, you and the nurses to encourage the baby's development. The infant educator recommends handling and developmental activities as well as soothing and feeding methods.

At Home

The follow-up nurse, Diane Valentin, visits you once the baby goes home, to help with information about development and care.

In the Follow-Up Clinic

The baby is seen every three months during the first year by the developmental pediatrician, Dr. Daly or Dr. Umansky, and by the infant educator to check the baby's developmental progress.

Finally, at one year of age the psychologist, Dr. Gardner or Dr. Turnbull, does a complete assessment of the infant's development, with suggestions to you about how to help the child's future development.

Children's Hospital Medical Center
of Northern California

51st and Grove Streets / Oakland, California 94609 / (415) 428-3000

PARENT EVALUATION FORM

I. Evaluation of Your Experience in the ICN

1. Overall, how would you rate your experiences while your baby was in the ICN? (please check one answer)

_____ Very Good _____ Good _____Poor

2. What were some of the good experiences for you while your baby was in the ICN?

3. What were some of the difficult experiences for you while your baby was in the ICN?

4. Who were the people who were most helpful to you as a parent in the ICN (for example, doctors, nurses, social workers, infant educators, therapists, other parents, other people), and how did they help?

5. Do you have any suggestions about how to make the ICN experience easier for parents?

(con. next page)

Parent Evaluation Form/con.

II. Evaluation of Your Experience With the ICN Interact Project

1. Overall, how helpful has the ICN Interact Project been for you and your baby?

_____ Very Helpful _____ Helpful _____ Not Helpful

2. Please check which parts of the project were helpful to you and describe how they helped:

_____Infant Educators in the ICN. How?

_____Follow-Up Nurse visits. How?

_____Follow-Up Clinic. How?

3. How is your baby doing developmentally now?

4. Does your baby have any problems which concern you?

5. Have your early experiences and the hospitalization of your baby affected how you feel as a parent?

6. Do you have any suggestions about how to make the ICN Interact Project more helpful to parents?

ICN INTERACT PROJECT

CHILDREN'S HOSPITAL, OAKLAND, CALIFORNIA

Model of Developmertal Intervention In the ICN
And Developmental Follow-Up For High Risk Newborns

The ICN Interact Project is a model program funded by the Handicapped Children's Early Education Programs (HCEEP) of Special Education Programs, U.S. Office of Education. Its purpose is preventative early intervention with newborns in the Intensive Care Nursery who are at great risk for handicapping conditions because of significant prematurity of other serious medical problems. These are the babies who are hospitalized for a month or more after birth. Lengthy hospitalization and the impact on the family thus compounds the baby's medical problems.

The ICN Interact Project is part of the Child Development Center which has multidisciplinary expertise in the prevention, diagnosis and treatment of developmental problems in children under age five. The Child Development Center in turn is part of Children's Hospital Medical Center in Oakland, a large pediatric medical center which serves only children.

The model program has two major service components:

I) Developmental Intervention In the Intensive Care Nursery

II) Developmental Follow-Up After Newborn Intensive Care

II. Model of Developmental Follow-Up After Newborn Intensive Care

Need for Developmental Follow-Up

Developmental follow-up for babies leaving the Newborn Intensive Care Nursery after lengthy hospitalizations is important for a number of reasons. The primary reason is that significantly premature and seriously ill newborns have been found to be at significantly greater risk for handicapping conditions than healthy full-term babies. By monitoring the early developmental progress of these babies, and providing appropriate developmental intervention as needed, handicapping conditions can be minimized and special needs identified early.

A second reason is the NICN procedures and successes are changing rapidly. Babies are being saved at earlier and earlier stages of prematurity. This generally means longer NICN hospitalizations while the very premature babies recuperate, gain weight and begin independent physiological regulation and feeding. It also means that these babies are being discharged at earlier sizes and ages, many prior to being totally well. A good example of this is the premature baby who goes home yet requires oxygen via nasal cannula for several months afterwards. Families with babies who go home not having recuperated fully need specialized information, assistance and support.

A third reason for follow-up of high risk infants is that both prematurity and lengthy hospitalizations of the newborn pose special stresses for the family and for the developing parent-child relationship. A developmental follow-up program, particularly if it reaches out to the infant and family at home, can prevent or reduce some of the subsequent environmental problems which can result for these special babies.

Target Population

Since the project is concerned with newborns who are hospitalized for one month or more, its population is the sickest and most premature babies in the ICN. Currently 95% of its population is less than 37 weeks gestational age, 83% is 31 weeks or less and 25% are term babies with serious medical problems. Length of ICN stay ranges from 5 to 65 weeks with a current average of almost 4 months.

Babies seen in the project are ethnically, geographically and culturally diverse. The area includes both urban Oakland, suburban areas and rural areas of California's agricultural valleys. Socio-economic status of parents ranges from the 15 year old single parent who has dropped out of high school to the college educated, financially secure nuclear family.

Because of the health , age and familial characteristics of these babies, certain types of problems and needs are common in follow-up. The premature babies all have had respiratory distress syndrome (RDS), and currently, 35% subsequently develop significant bronchopulmonary dysplasia (BPD). Most (60%) of these babies with BPD go home on oxygen. Approximately 25% have some stage of retinal damage, retrolental fibroplasia (RLF). Other problems such as asphyxia, congenital anomalies, or being large for gestational age are encountered occasionally.

Babies with known or highly likely handicaps at birth are not admitted to the project (though they do receive developmental intervention in the ICN). Since it is certain that they will need more intensive early intervention services, they are referred at discharge to infant programs and relevant community agencies. The project's population is therefore only infants at risk for handicapping conditions, though some handicaps become evident during the ICN or follow-up phase.

Philosophy and Structure of Follow-Up

Our model for follow-up of these high risk babies is based on an essential premise that the special needs and potential outcomes for these infants and families are varied, so therefore follow-up and intervention must be individually tailored. Since most of these babies have the potential for a normal developmental outcome, intervention is supportive and low-key, reinforcing the parent's central role as the primary developmental influence on the baby. If a concern about the infant's development occurs during follow-up, the staff also attempts to assist the family in clarifying their understanding and reactions to that special need. A primary focus in follow-up, as in developmental intervention in the ICN, is to facilitate the emerging parent-child relationship which is often jeopardized by the baby's special needs and characteristics, the precipitous and traumatic neonatal period, and the lengthy hospitalization.

The follow-up model has three essential components:

1) home follow-up
2) developmental clinic follow-up
3) coordination with and referral to other resources

The follow-up program begins while the baby is still in the ICN. The infant educators introduce the family to the follow-up nurse who will be a major resource for them once the baby is ready to be transferred to a secondary care hospital or to home.

The follow-up nurse is an appropriate resource for these families since many of the early concerns are health and care-related. The follow-up nurse has competencies both in nursing and as a developmental specialist. An important characteristic of her expertise is experience both as an ICN nurse and as a publich health nurse who has worked with families at home.

Home Follow-Up

A key factor in the efficacy of the follow-up program is the relationship between family and staff. This begins in the ICN and expands to include the follow-up nurse when the baby goes home. The follow-up nurse visits the home frequently in the early months, in order to sustain and develop a supportive relationship by being available to the family during the particularly difficult period of the baby's homecoming.

The nurse is in phone contact with the family in the first days after discharge. She schedules an immediate home visit within the first week or two. She generally will make a second visit in the first month, then monthly visits for the first six months, reduced to bi-monthly visits in the second six months. The schedule is flexible and is altered to meet the family's specific needs. Some families require more frequent visits during the critical early months, while others need only an occasional visit.

Because the baby has received intensive care and usually is a premature baby, health-realted concerns predominate in early visits. Parents usually have many questions about feeding and growth, visitors and exposure to unknown infections, rashes, room temperatures, dressing the baby, immunizations, and most importantly, when to call their pediatrician. Special care requirements such as oxygen, tracheostomy or gastrostomy care and other technical questions are not uncommon.

Beyond urgent health care questions are other concerns in the baby's adjustment to being at home. One common concern is the baby's inconsistent sleep schedule and how to help the baby settle into a regular sleep pattern after the atypical ICN beginning.

Developmental concerns usually emerge very quickly. The nurse attempts to help the parent adjust the home to the baby and provide developmentally appropriate experiences. Since many of the premature babies do not look or behave like a full term baby the nurse can be a helpful and reassuring guide for the parent.

Finally, aiding the adjustment of the parent and family is an important purpose for home visits. The traumatic early beginnings leaves an indelible mark on the parent. Som parents adjust to and move beyond this experience more easily than others. Opportunities to discuss early experiences and current perceptions are helpful to some.

The baby may continue to present unanticipated behavioral problems to the family. The baby who is small for gestational age (SGA) or who has BPD is more likely to be irritable and difficult to soothe. Or the baby may seem less responsive than others. In each of these common situations the parents may feel that they, rather than the baby, are having difficulties. Support for their abilities as parents is an important accomplishment for follow-up. The nurse can accomplish this by assisting the parent in interpreting the baby's cues and behavior. She can also make very practical suggestions for methods for soothing and arousing the baby. The nurse's interactions with the parent are based in part on a formal assessment of parent-

infant interactions shortly after the baby goes home and then later in the first year. Assessments and suggestions are interrelated with those of the infant educator and other staff involved in follow-up.

Neonatal Follow-Up Clinic

As part of the follow-up program infants return every three months for multidisciplinary developmental examinations. During the clinic visit they are seen by a developmental pediatrician, the infant educator and the follow-up nurse. They also may be seen by a nutritionist or physical therapist if those types of evaluations are indicated. In the final clinic visit the developmental psychologist carries out a formal developmental evaluation, using the Bayley Scales of Infant Development and other developmental assessments as appropriate.

Each of these disciplines contributes their perspective on the development of the infant and family concerns. These visits are not for the purpose of providing primary health care, but rather for specific developmental monitoring. However, these visits are closely coordinated with the pediatrician or other primary health care provider; if any problems are apparent in the baby getting primary health care the developmental staff can help insure that it is obtained.

The pediatrician evaluates the child medically and developmentally, with a particular emphasis on monitoring the baby's neurological status. Medical tests and assessments of vision or hearing may be requested. The infant educator assesses the baby's progress since last seen and offers suggestions to the parent regarding developmental activities and expectations. The follow-up nurse coordinates the visit and also completes an assessment of parent-infant interactions under the moderate stress of the pediatric exam. The nurse will even transport the family to and from the clinic visit if needed.

At 12 months of age (if emerging handicapping conditions do not warrant sooner) the final clinic visit and psychologist's assessment is followed by multidisciplinary case review and final disposition. Children who are believed to be developing normally at one year corrected age are terminated from follow-up. Children and families for whom there are clear concerns are referred to community resources as appropriate and available. Infants about whom there are questions are scheduled for continued developmental follow-up at the Child Development Center six months to one year later.

Coordination With Community Resources

Throughout the follow-up year, coordination with ICN and community resources who are, or could be involved with each infant, is an important task of the follow-up nurse. Coordination is essential, not only because of the special needs of infant and family, but also because these babies ususally are involved with many health specialists and other professionals.

Communication with the primary health care providers is particularly important. When the baby is discharged from the ICN a letter is sent to the pediatrician to explain the procedures and purposes of the follow-up program. After each clinic visit copies of the assess-

ments and reports are sent to the pediatrician as well. As specific concerns arise the nurse or other staff may discuss them directly with the pediatrician.

The follow-up nurse also coordinates other activities such as audiology testing, opthalmologic exams, pulmonary evaluations or other clinic assessments. She seesthat referrals to community resources such as supplemental food programs and infant development programs are accomplished satisfactorily. If involvement of public health nurses or child protective workers is appropriate she coordinates her efforts with theirs.

A unique facet of the follow-up nurse's role as a coordinator of services is as a liason and conduit of information between the family, ICN, and as needed, the secondary care nursery. If the baby is tranferred to a secondary care nursery the follow-up nurse helps prepare the family for what to expect and assists both the family and secondary care nurses in the transition.

Once the baby goes home the follow-up nurse also provides feedback to the ICN nursing and medical staff about the baby's progress and the family's perspective on their experiences in the ICN. After home visits the follow-up nurse posts pictures of the ICN graduates with a brief progress report in the ICN staff lounge for all shifts to see. The ICN neonatologists are given copies of follow-up clinic reports which may be discussed during the weekly multidisciplinary ICN rounds.

Formal feedback is also obtained from the parent at the end of follow-up when the parent is asked to evaluate and comment on both the project and their ICN experiences. Through these formal and informal communications the project is able to provide feedback which may improve ICN experiences for subsequent families, and which support the positive efforts of ICN staff which are already occurring.

The Parent-Infant Project Outreach Component and
I.C.N. Interact Project, Child Development Center,
Children's Hospital Medical Center (CHMC),
are sponsoring a conference:

Monday, June 1, 1981, 8:30 a.m. to 4:40 p.m.
Marriott Inn, Berkeley Marina, 200 Marina Blvd.
(foot of University Ave., at the bay—directions, over)

The Intensive Care Nursery: Intervention and Follow-Up

	8:00 - 8:30	Registration
I.	8:30 - 8:45	RICHARD UMANSKY, M.D., Director, Child Development Center, CHMC; and NANCY SWEET, M.A., Administrative Director of I.C.N. Interact Project, CHMC, and Director, Parent-Infant Project: Opening Remarks
		Moderator: RICHARD UMANSKY, M.D.
II.	8:45 - 9:30	PETER GORSKI, M.D., Director of Developmental & Behavioral Pediatrics, Mt. Zion Hospital & Medical Center, S.F.: Behavioral Observations of Preterm Infants: Caring about Development
III.	9:30 - 10:15	FRAN KNUDTSON, M.A., Psychologist, Agency for Infant Development, Marin County: Working with Parents of Prematures
	10:15 - 10:45	Break
IV.	10:45 - 11:45	KATHY VANDENBERG, M.A., and BETTE FLUSHMAN, M.A., Infant Educators, and CAROLYN LUND, M.S.N., Clinical Specialist; I.C.N. Interact Project, CHMC: Humanizing the Intensive Care Nursery for Infants, Parents and Staff
	11:45 - 12:00	Question-and-Answer Period
	12:00 - 1:00	Lunch
		Moderators: BETTE FLUSHMAN, M.A., & NANCY SWEET, M.A.
V.	1:00 - 1:45	Panel: CAROLYN LUND, M.S.N. and DIANE VALENTIN, R.N., B.A., Follow-Up Nurse, I.C.N. Interact Project, CHMC; and JULIE WILSON, R.N., P.H.N., Alameda County Health Dept.: Transition to Home, and Public Health Nurse Follow-Up
VI.	1:45 - 2:15	JANE HUNT, Ph.D., Associate Research Psychologist, Institute of Human Development, U.C. Berkeley: Follow-Up Studies of I.C.N. Graduates at U.C.S.F.
	2:15 - 2:45	Break
VII.	2:45 - 3:15	BARBARA GAFFIELD, M.S., R.D., Nutritionist, Child Development Center, CHMC: Feeding the Premie at Home
VIII.	3:15 - 4:15	Parent Panel: ALISON WALSH, Administrative Clinic Coordinator, Newborn I.C.U. Follow-Up, Children's Hospital, S.F.; SUSAN & RICH FULLER, JUDY STODDARD and MIDGE CALLAHAN, Parents, Parent-to-Parent Group Members, Children's Hospital, S.F.: Parent Concerns and Response to the Intensive Care Nursery
	4:15 - 4:30	Question-and-Answer Period
	4:30 - 4:40	Closing Remarks, Evaluation Questionnaires, and Adjournment

more information, over . . .